

VOR

*Speaking out
for people with mental retardation*

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Don't Rob Peter to Pay Paul:

**Maintaining choice and achieving better outcomes
in Medicaid residential facilities
for people with mental retardation**

**By Irene Welch
VOR Representative**

**March 14, 2006
Medicaid Commission Meeting**



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INTRODUCTION

My name is Irene Welch¹. I am a VOR member. VOR is a national advocacy organization which advocates for people with mental retardation. I am here in particular on behalf of my niece, Mary Elizabeth, who has profound mental retardation, cerebral palsy, a complex seizure disorder, together with additional disabilities and chronic medical concerns. She and her housemates have never spoken. Some use 2 or three signs such as "eat," "drink," "toilet," or "more."

Mary Elizabeth lives in a state-operated group home in Massachusetts and goes every day to a day program at a state-operated Intermediate Care Facility for People with Mental Retardation – an ICF/MR. Her daily routine, relying on a combination of community and facility supports, mirrors VOR's overall mission in support of a full array of residential and service options for people with mental retardation.

Today, you, the Commission members, are focusing on access, quality and the cost of Medicaid long-term care services by considering the question:

**"How do we get the best quality acute care and
preventive care for our public dollars?"**

In an attempt to answer your question, I will focus my comments first on the people with mental retardation in need of services, second upon the quality of available service systems for this population, and third, upon a cost-effective solution being used currently in a few states to reduce costs, enhance quality community options by indefinitely preserving the family unit.

¹REQUIRED FINANCIAL DISCLOSURE: I do NOT have any financial involvement related to any services being discussed.

FIRST: THE PEOPLE BEING SERVED BY ICFs/MR

To fully appreciate the need for ICFs/MR, we need to consider the people being served.

79.3% of all people in state operated ICFs/MR have severe and profound mental retardation. A majority of these residents have additional functional limitations associated with walking, communicating, eating, dressing, and/or toileting. A majority have additional disabling conditions, such as cerebral palsy, behavioral or psychiatric disorders². Most people living in ICFs/MR also have chronic medical conditions. Because of the severity of their multiple handicaps, especially their significant cognitive disabilities and medical fragility, these folks require access to on site medical and health care services in ICFs/MR around the clock, 7 days a week.

SECOND: THE QUALITY OF CARE: ICFs/MR v. THE COMMUNITY

To remain certified and funded, ICFs/MR must meet 378 specific standards within 8 conditions of participation in major quality of care categories which are evaluated on an annual basis by CMS regional teams. These stringent requirements ensure that high quality care is being consistently delivered to the most vulnerable citizens of our society. Part of the annual review requires documentation that each and every resident, in fact, currently needs the ICF/MR level of care.

In contrast, as the deinstitutionalization movement has grown, there has been a corresponding increase in state audits, investigative media series and peer-reviewed studies documenting systemic abuse, neglect and death associated with community-based services for people with mental retardation³. The community infrastructure is also plagued by a well documented staffing crisis in each and every state. The staffing crisis is characterized by high turnover, low wages, inadequate training, and a ballooning waiting list for services. Against this backdrop removing people from their facility homes to the documented dangers and uncertainties and isolation of community "homes" is unconscionable.

Robbing Peter to pay Paul is not a solution. We have a better idea.

THIRD: THE SOLUTION

Community Resource Centers are a proven model of cost-effective, high quality community-based long-term care options, including health care. With this model, people residing in the community access ICF/MR-based health care expertise on an outpatient basis. States that provide this option are currently using the existing infrastructure to help families maintain their loved ones in the family home with supports from the expert

² Robert Prouty, Gary Smith, and K. Charlie Lakin (eds.) (2005). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institution on Community Integration.

³ See, http://www.vor.net/abuse_neglect.htm

practitioners based at ICFs/MR. Services offered through this model include respite, dental care, medical and nursing care, equipment modification, communication technological support, speech, recreation, day services, evaluations and assessments, and a whole host of therapies (OT, PT, pool, equestrian, sensory, etc.), and much more. By eliminating or delaying the need for full residential care, states save millions of dollars and families stay together.

CONCLUSION

VOR supports a full array of residential options. While we have very serious concerns about the community's ability to safely serve all the residents of ICFs/MR, we absolutely support any initiative to better fund and expand community service options, so long as the solution does not include eliminating access to existing facility services for those few people with mental retardation who truly need that level of care..

Providing consumers a choice between home and community-based supports and ICFs/MR is supported by federal statutory and case law, including *Olmstead* and Medicaid⁴. The "least restrictive environment" can be a facility setting, where opportunities for inclusion in community events are often abundant. It is not uncommon for residents of state operated facilities to enjoy in any given week trips to the mall, movies, restaurants, parks, fairs, concerts and beach.

This Commission has been praised by the Congressional Quarterly for displaying "the kind of concentration, curiosity, and passion that suggested their concern about the stakes involved."

For VOR members, the "stakes involved" are our very fragile family members. The deliberations by Commission members take on a life or death aspect for our loved ones.

We can't express strongly enough how much we appreciate your effort to carefully consider every aspect of this very serious debate.

Thank you very much this opportunity to present our perspective before the Medicaid Commission.

⁴ See e.g., *Olmstead v. L.C.*, 119 S. Ct. 2176, 2185 (1999), in which the Supreme Court held that unjustified institutionalization is discrimination under the Americans with Disabilities Act, with choice of the individual being a required criteria in determining whether community placement was required. To emphasize the importance of choice, and the ongoing role for publicly and privately-operated institutions, the Supreme Court stated: "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." 119 S. Ct. at 2187.

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CHARACTERISTICS OF RESIDENTS OF LARGE STATE MR/DD FACILITIES

Source:

Research and Training Center on Community Living
Institute on Community Integration/UCEDD
University of Minnesota

July 2005

Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004

July 2005

**Research and Training Center on Community Living
Institute on Community Integration/UCEDD**



The College of Education
& Human Development

UNIVERSITY OF MINNESOTA

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Chapter 3

Characteristics and Movement of Residents of Large State Facilities

K. Charlie Lakin, Robert W. Prouty, Kathryn Coucouvanis and Soo Yong Byun

This chapter provides information about the characteristics and movement of residents of large state residential facilities for persons with intellectual disabilities/developmental disabilities (ID/DD) in FY 2004. It is based on a survey of all large state-operated facilities for persons with ID/DD with 16 or more residents or distinct ID/DD units for 16 or more persons within large state facilities primarily serving other populations. A description of the state facility survey is provided in the "Methodology" section ("Individual State Residential Facility Survey").

Characteristics of Residents

Table 1.14 presents a summary of selected age, diagnostic and functional characteristics of residents of large (16 or more residents) state ID/DD residential facilities for persons with ID/DD (hereafter "large state facilities") on June 30 of 1977, 1987, 1998, 2000, 2002 and 2004.

Age of Residents

There has been a continuing aging of the population of residents of large state facilities since 1977. Age statistics are based on reporting large state facilities for June 30 of 1977, 1987, 1991, 1996, 1998, 2000, 2002 and 2004. These statistics are based on

Table 1.14 Characteristics of Residents of Large State ID/DD Facilities from June 30, 1977 through June 30, 2004

| Characteristic | June 30 of the Year | | | | | | | |
|----------------------------------|--|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|------|
| | 1977 (N=151,112) | 1987 (N=94,695) | 1996 (N=58,320) | 1998 (N=51,485) | 2000 (N=47,329) | 2002 (N=44,066) | 2004 (N=41,653) | |
| Age | 0-21 Years | 35.8% | 12.7% | 5.0% | 4.8% | 4.5% | 4.5% | 4.3% |
| | 22-39 Years | 41.3 | 54.1 | 44.6 | 38.1 | 34.4 | 30.9 | 26.0 |
| | 40-62 Years | 19.2 | 27.3 | 42.7 | 48.9 | 52.7 | 55.4 | 59.9 |
| | 63+ Years | 3.7 | 6.0 | 7.7 | 8.2 | 8.4 | 9.2 | 9.8 |
| Level of Intellectual Disability | Mild/No ID | 10.4 | 7.2 | 7.4 | 7.6 | 10.2 | 10.4 | 10.2 |
| | Moderate | 16.4 | 9.8 | 8.9 | 9.5 | 9.8 | 9.9 | 10.5 |
| | Severe | 27.6 | 20.0 | 17.8 | 18.3 | 17.7 | 17.7 | 17.7 |
| | Profound | 45.6 | 63.0 | 65.9 | 64.6 | 62.3 | 62.0 | 61.6 |
| Additional Conditions | Cerebral Palsy | 19.3 | 20.5 | 22.6 | 23.5 | 21.9 | 19.4 | 21.8 |
| | Behavior Disorder | 25.4 | 40.7 | 45.7 | 44.4 | 47.4 | 52.4 | 49.2 |
| | Psychiatric Disorder | NC | NC | 31.0 | 34.3 | 42.0 | 45.7 | 44.3 |
| Functional Limitations | Needs assistance or supervision walking | 23.3 | 29.5 | 35.7 | 38.9 | 35.4 | 37.0 | 36.8 |
| | Cannot communicate basic desires verbally | 43.5 | 54.8 | 59.4 | 59.6 | 59.4 | 58.1 | 54.9 |
| | Needs assistance or supervision in toileting | 34.1 | 46.6 | 57.0 | 59.5 | 55.9 | 56.1 | 53.6 |
| | Needs assistance or supervision in eating | 21.4 | 37.8 | 50.9 | 56.4 | 48.4 | 51.4 | 51.0 |
| | Needs assistance or supervision in dressing self | 55.8 | 60.5 | 66.1 | 69.9 | 65.3 | 62.6 | 59.8 |

NC = statistic not collected in that year

The 2004 data are based on reports of large state facilities housing 81.5% to 86.3% (depending on the characteristic) of the 41,653 large state facility residents on June 30, 2004. Response rates obtained in earlier years shown ranged from 76.0% to 91.5%.

the reports of state facilities housing 81.5% of all residents on June 30, 2004 (and between 76% and 91.5% in earlier years). As shown in Table 1.14, the proportion of children and youth (birth to 21 years) living in large state facilities declined from 35.8% of all residents in 1977 to 4.3% of all residents in June 2004. Despite the substantial increase in the proportion of residents 63 years and older in large state facilities, from 3.7% in 1977 to 9.8% in 2004, the total number of residents 63 and older actually decreased by about 1,310 residents (to an estimated 4,082) between 1977 and 2004.

The most notably changing age cohort of state facility residents in recent years has been that of "middle age" persons (40-62 years). Between 1991 and 2004 this group grew from 32.5% to 59.9% of all large state facility residents, as the demographics of the "baby boom" became increasingly evident. In June 2004, 69.7% of all large state facility residents were 40 years or older. This compares to 22.9% in June 1977, 33.3% in June 1987, 50.4% in June 1996 and 64.6% in June 2002.

Despite the rapid proportional growth in persons 40 years and older, between June 30, 1996 and June 30, 2004, the actual number of individuals 40 years and older living in large state facilities decreased by more than 400 persons. The overall decrease in large state facility residents who were 40 years or older was entirely attributable to the decreased number of residents who were 63 or older. In June 2004 the estimated number of residents in the 40-62 group was almost exactly the number as estimated

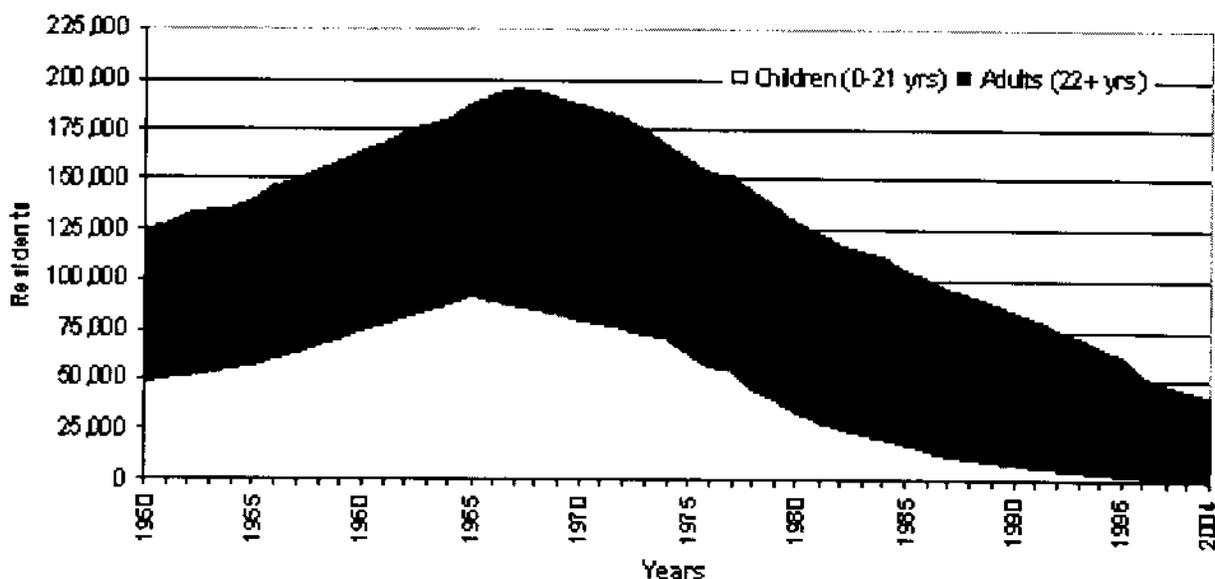
in June 1996 (24,905 and 24,903 respectively), while and the number of persons 63 or older decreased by about 410. As will be evident from admission statistics presented later, the shifts among the age categories during the last eight years was primarily because the stable residential population of the large state facilities grew older and "aged out" of the young adult category (22-39 years) and into the middle-aged category. Middle-aged individuals being admitted to large state facilities contributed relatively little to these shifts.

As shown in Figure 1.7, the June 30, 2004 estimate of 1,771 children and youth (0-21 years) making up 4.3% of the large state facility population nationwide reflects the dramatic decreases during the second half of this century and particularly the past quarter century. In 1950, 48,354 of the 124,304 large state facility residents (38.9%) were 21 years or younger. By 1965 the population of children and youth had increased to 91,592 and made up 48.9% of all large state facility residents. Subsequent annual decreases brought the population of children and youth to 54,098 (35.8%) in 1977, 12,026 (12.7%) in 1987, 6,908 (8.7%) in 1991, 2,916 (5.0%) in 1996, 2,130 (4.5%) in 2000, 1,983 in June 2002 (4.5%) and eventually to 1,771 in June 2004 (4.3%).

Level of Intellectual Disability

Table 1.14 also presents a breakdown of the reported level of intellectual disability of residents of large state facilities on June 30 of 1977, 1987,

Figure 1.7 Total and Childhood (0-21 Years) Populations of Large State ID/DD Facilities, 1950-2004



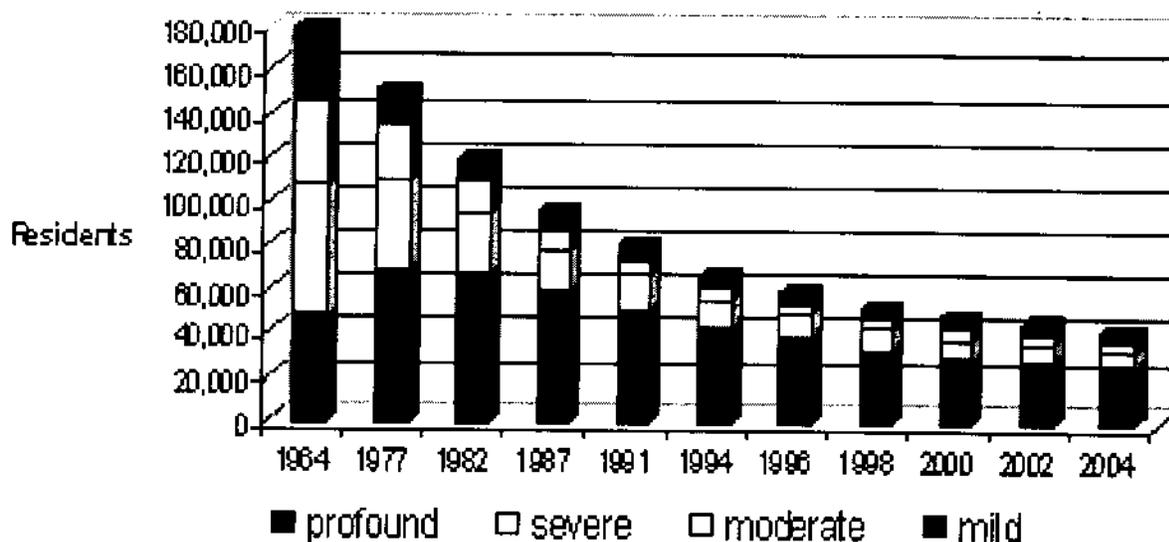
1996, 1998, 2000, 2002 and 2004. In 2004, based on the reports of facilities housing 81.5% of all large state facility residents, there were an estimated 4,268 large state facility residents with mild or no intellectual disability (10.2% of all residents) as compared with an estimated 15,716 in 1977, 6,818 in 1986, 4,316 in 1996, and 3,913 in 1998. Between 1998 and 2000 the proportion and total number of state institution residents with mild or no intellectual disability increased by about 900 persons but has slowly decreased at a rate about equal to overall facility depopulation, and 4,826 in 2000 and 4,583 in 2002. It is notable that the proportion of persons with mild or no intellectual disabilities in large state facilities, after having decreased by each year since 1962, from 20.7% in 1962 to 7.4% in 1996, began increasing in 1998 (to 7.6%) and continued to 2000 (to 10.2%). Since then it appears to have stabilized at about 10.2% to 10.4% of all residents. There were approximately 355 more persons with mild or no intellectual disabilities in large facilities in June 2004 than there were in June 1998.

Between 1996 and 2004 populations of persons with moderate and severe intellectual disability decreased slightly more rapidly than large state facility residents as a whole. The proportion of large state facility populations with profound intellectual disabilities increased substantially from 1977 to 2004, from 45.6% residents to 61.6% of all residents, but between 1996 and 2004 that proportion decreased (from 65.9% to 61.6%).

Despite the general increases in the proportion of residents with profound intellectual disabilities between 1977 and 2004, their actual numbers decreased by about 43,250 people, from 68,907 to an estimated 25,660 people. Between June 30, 1987 and June 30, 2004 the number of large state facility residents with profound intellectual disability decreased by almost 34,000 people or 57.0%. Between June 1996 and June 2004 residents with profound intellectual disability decreased by about 12,800 persons.

Figure 1.8 shows the same basic statistics as those in Table 1.14 with the addition of 1964 and 1982 surveys (Scheerenberger, 1965, 1983). It shows that between 1964 and 1977, while large state facility populations decreased by about 38,500 residents, the number of residents with profound intellectual disabilities actually increased by about 20,000. During the same period the number of large state facility residents with mild, moderate, severe or no intellectual disabilities decreased by nearly 50,000 people from 131,100 to 82,000. However, since 1977 and more notably since 1987, persons with profound intellectual disabilities have been decreasing among large state facility populations at rates similar to, indeed slightly faster than, persons with less severe intellectual impairments.

Figure 1.8 Level of Intellectual Disability of Residents of Large State ID/DD Facilities on June 30 of Selected Years, 1964-2002



Functional Characteristics

Table 1.14 also shows the percentage of residents of large state facilities reported to have functional limitations in various important activities of daily living. In this study, each of the large state facilities surveyed was asked to report the number of their residents who: 1) "cannot walk without assistance or supervision," 2) "cannot communicate basic desires verbally," 3) "cannot use the toilet without assistance or supervision," 4) "cannot feed self without assistance or supervision" and 5) "cannot dress self without assistance or supervision." National statistics for 2004 are shown in Table 1.14 with comparable statistics from 1977, 1987, 1996, 1998, 2000, 2002 and 2004.

Between 1987 and 1996 there was an increasing proportion of large state facility residents with functional limitations requiring assistance. Between 1996 and 2004 the proportions of residents reported to require assistance with activities of daily living remained quite stable. In 2004, 36.8% of large state facility residents were reported to need assistance or supervision in walking and 54.9% to be unable to communicate basic desires verbally. Over half (53.6%) of large state facility residents were reported to be unable to use the toilet independently without assistance or supervision. Half (51.0%) were reported to be unable to feed themselves without assistance or supervision. More than three-fifths (59.8%) of residents were reported to need assistance or supervision in getting dressed.

Between 1987 to 2004 there were increases in the percentage of residents with substantial limitations in toileting themselves (46.6% to 53.6%) and feeding themselves (37.8% to 51.0%). Again, however, the proportion of residents with limitations in these areas were lower in June 2004 than in June 1998. As will be shown subsequently, there was considerable interstate variation around these averages.

Age by Level of Intellectual Disability

Table 1.15 shows the distribution of residents of large state facilities by age and level of intellectual disability. Facilities housing 81.5% of all residents on June 30, 2004 reported this distribution. Clearly middle-aged residents (40-62 years) were more likely to have profound cognitive limitations than residents who were relatively younger or older. Only 57.0% of residents 63 or older and 56.1% of residents 22-39 years had profound intellectual disabilities as compared with 67.1% of 40-54 year olds and 64.1% of 55-62 year olds. Children and youth (0-21 years and young adults 22-39 years) tended to have less severe intellectual disabilities than the general population of residents. This continued a trend beginning in 1998 with a notable increase in the number of adolescents and young adults (15-21 years) with mild or moderate intellectual disabilities between June 1998 and June 2004, from an estimated total of 695 (adjusted for non-reporting) in 1998 to 811 in 2004.

One of the most remarkable demographic statistics is that a substantial majority of large state facility

Table 1.15 Distribution of Residents of Large State Facilities by Level of Intellectual Disability and Age on June 30, 2004

| Level of Intellectual Disability | Chronological Age in Years | | | | | | | Total |
|----------------------------------|----------------------------|---------------------------|-----------------------------|-------------------------------|-------------------------------|------------------------------|-----------------------------|--------------------------------|
| | 0-9 | 10-14 | 15-21 | 22-39 | 40-54 | 55-62 | 63+ | |
| Mild + | 1 (0.0%) [3.3%] | 40 (0.9%) [18.3%] | 488 (11.4%) [31.7%] | 1,724 (40.4%) [15.9%] | 1,349 (31.6%) [7.0%] | 348 (8.2%) [6.0%] | 318 (7.5%) [7.8%] | 4,268 (100.0%) [10.2%] |
| Moderate | 5 (0.1%) [13.3%] | 45 (1.0%) [20.6%] | 323 (7.4%) [21.0%] | 1,368 (31.3%) [12.7%] | 1,712 (39.2%) [8.9%] | 505 (11.6%) [8.8%] | 410 (9.4%) [10.0%] | 4,368 (100.0%) [10.5%] |
| Severe | 9 (0.1%) [26.7%] | 35 (0.5%) [16.1%] | 184 (2.5%) [12.0%] | 1,648 (22.4%) [15.2%] | 3,244 (44.0%) [16.9%] | 1,218 (16.5%) [21.1%] | 1,034 (14.0%) [25.3%] | 7,372 (100.0%) [17.7%] |
| Profound | 21 (0.1%) [56.7%] | 98 (0.4%) [45.0%] | 542 (2.1%) [35.3%] | 6,069 (23.7%) [56.1%] | 12,886 (50.2%) [67.1%] | 3,695 (14.4%) [64.1%] | 2,334 (9.1%) [57.0%] | 25,645 (100.0%) [61.6%] |
| Total | 36 (0.1%) [100.0%] | 218 (0.5%) [100.0%] | 1,537 (3.7%) [100.0%] | 10,809 (26.0%) [100.0%] | 19,191 (46.1%) [100.0%] | 5,766 (13.8%) [100.0%] | 4,096 (9.8%) [100.0%] | 41,653 (100.0%) [100.0%] |

Note: The percentage in parentheses indicates the distribution of persons by age with different levels of intellectual disability. The percentage in brackets indicates the distribution of persons by levels of intellectual disability within the different age categories. Statistics are based estimates on the reports of state facilities housing 33,930 of 41,653 (81.5%) residents of large state facilities on June 30, 2004.

Table 1.16 Gender Distribution of Residents of Large State Facilities by State on June 30, 2004

| State | Gender of Residents (%) | | Total |
|------------|-------------------------|--------|-------|
| | Male | Female | |
| AL | 63.8 | 36.2 | 100.0 |
| AK | NA | NA | NA |
| AZ | 50.7 | 49.3 | 100.0 |
| AR | 66.7 | 33.3 | 100.0 |
| CA | 60.0 | 40.0 | 100.0 |
| CO | 79.1 | 20.9 | 100.0 |
| CT | DNF | DNF | DNF |
| DE | 49.6 | 50.4 | 100.0 |
| DC | NA | NA | NA |
| FL | 71.5 | 28.5 | 100.0 |
| GA | 59.6 | 40.4 | 100.0 |
| HI | NA | NA | NA |
| ID | DNF | DNF | DNF |
| IL | 66.3 | 33.7 | 100.0 |
| IN | 68.7 | 31.3 | 100.0 |
| IA | 69.5 | 30.5 | 100.0 |
| KS | 69.6 | 30.4 | 100.0 |
| KY | 64.5 | 35.5 | 100.0 |
| LA | 59.7 | 40.3 | 100.0 |
| ME | NA | NA | NA |
| MD | 64.3 | 35.7 | 100.0 |
| MA | 61.6 | 38.4 | 100.0 |
| MI | 75.9 | 24.1 | 100.0 |
| MN | 65.4 | 34.6 | 100.0 |
| MS | 56.6 | 43.4 | 100.0 |
| MO | 63.3 | 36.7 | 100.0 |
| MT | 66.3 | 33.7 | 100.0 |
| NE | 60.0 | 40.0 | 100.0 |
| NV | 72.8 | 27.2 | 100.0 |
| NH | NA | NA | NA |
| NJ | 68.2 | 31.8 | 100.0 |
| NM | NA | NA | NA |
| NY | 74.1 | 25.9 | 100.0 |
| NC | 57.9 | 42.1 | 100.0 |
| ND | 60.7 | 39.3 | 100.0 |
| OH | 62.6 | 37.4 | 100.0 |
| OK | 68.8 | 31.2 | 100.0 |
| OR | 72.7 | 27.3 | 100.0 |
| PA | 53.8 | 46.2 | 100.0 |
| RI | NA | NA | NA |
| SC | 62.8 | 37.2 | 100.0 |
| SD | 71.6 | 28.4 | 100.0 |
| TN | 54.3 | 45.7 | 100.0 |
| TX | 58.0 | 42.0 | 100.0 |
| UT | 59.6 | 40.4 | 100.0 |
| VT | NA | NA | NA |
| VA | 61.2 | 38.8 | 100.0 |
| WA | 61.1 | 38.9 | 100.0 |
| WV | NA | NA | NA |
| WI | 61.4 | 38.6 | 100.0 |
| WY | 51.5 | 48.5 | 100.0 |
| U.S. Total | 63.1 | 36.9 | 100.0 |

NA= not applicable (state without large state facilities)
DNF= data not furnished or insufficient reporting (60% or fewer of residents included)

residents (54.4%) are non-elderly adults (ages 22-62 years) with profound intellectual disabilities. Over three-quarters (75.1%) of large state facility residents are adults between 22 years and 54 years old.

State-by-State Resident Characteristics

State-by-state statistics on resident characteristics are based on aggregated data on all reporting large state facilities in each state. State breakdowns are provided only for states in which the reporting facilities for any specific characteristics housed at least 60% of all large state facility residents.

Gender of Residents

Table 1.16 shows the distribution of large state facility residents by gender. In all states but Delaware, the majority of residents were male. Nationally, 63.1% of residents were male, with states ranging from lows of less than 55% in Arizona, Delaware, Pennsylvania and Wyoming to more than 75% in Colorado and Michigan. The proportion of male large state facility residents has slowly increased in recent years (57.0% in 1977, 57.4% in 1982, 59.0% in 1989, 58.5% in 1991, 59.3% in 1994, 60.0% in 1996, 60.4% in 1998, 61.0% in 2000, 62.8% in 2002 and 63.1% in 2004).

Age Distribution of Residents

Table 1.17 presents the state-by-state age distribution of residents in large state facilities on June 30, 2004. The table shows the great variability across states in the ages of residents. Differences were particularly notable in the number of children and youth (0-21 years) and the number of older residents (55 years and older).

Nationwide, 4.3% of all large state facility residents were 21 years or younger. Eight states reported 10.0% or more of their large facility residents as being in the 0-21 year age range (2 more than in 2002, but fewer than the number in 1991). In 1996 and 2004, 47 states reported statistics for at least 60% of the total large state facility population in both years. In all but 11 of these states there was a reduction in the proportion of residents 21 years and younger or total closure of large public facilities. There was an actual decrease in the number of residents 21 years and younger in all but 3 states.

Nationally 23.6% of large state facility residents were 55 years and older, as compared with 14.9% in 1996, 16.8% in 1998, 18.4% in 2000 and 20.4% in 2002. Individual states ranged from more than a quarter of all residents being 55 years and older in

Table 1.17 Age of Residents of Large State Facilities by State on June 30, 2004

| State | Age of Residents in Years (%) | | | | | | Total |
|------------|-------------------------------|-------|-------|-------|-------|------|-------|
| | 0-14 | 15-21 | 22-39 | 40-54 | 55-62 | 63+ | |
| AL | 0.0 | 0.0 | 21.1 | 47.7 | 16.1 | 15.1 | 100.0 |
| AK | NA | NA | NA | NA | NA | NA | NA |
| AZ | 0.0 | 0.0 | 4.3 | 57.9 | 30.0 | 7.9 | 100.0 |
| AR | 0.7 | 5.0 | 31.0 | 49.6 | 12.0 | 1.8 | 100.0 |
| CA | 0.4 | 3.8 | 40.5 | 39.1 | 10.7 | 5.5 | 100.0 |
| CO | 0.0 | 3.3 | 45.3 | 40.2 | 7.1 | 4.1 | 100.0 |
| CT | DNF | DNF | DNF | DNF | DNF | DNF | DNF |
| DE | 0.0 | 0.0 | 21.5 | 48.1 | 14.1 | 16.3 | 100.0 |
| DC | NA | NA | NA | NA | NA | NA | NA |
| FL | 0.0 | 7.7 | 31.4 | 43.4 | 10.8 | 6.7 | 100.0 |
| GA | 0.9 | 6.5 | 30.9 | 43.6 | 10.7 | 7.5 | 100.0 |
| HI | NA | NA | NA | NA | NA | NA | NA |
| ID | DNF | DNF | DNF | DNF | DNF | DNF | DNF |
| IL | 0.1 | 2.1 | 32.4 | 48.2 | 11.4 | 5.7 | 100.0 |
| IN | 0.0 | 2.3 | 38.1 | 45.2 | 11.1 | 3.4 | 100.0 |
| IA | 2.8 | 12.1 | 26.5 | 40.0 | 13.0 | 5.5 | 100.0 |
| KS | 1.3 | 4.9 | 33.1 | 50.9 | 6.7 | 3.1 | 100.0 |
| KY | 0.0 | 21.3 | 28.9 | 32.7 | 15.6 | 1.6 | 100.0 |
| LA | 4.6 | 12.8 | 34.3 | 31.9 | 9.8 | 6.6 | 100.0 |
| ME | NA | NA | NA | NA | NA | NA | NA |
| MD | 0.0 | 3.4 | 24.9 | 49.3 | 15.4 | 6.9 | 100.0 |
| MA | 0.0 | 0.0 | 7.9 | 41.7 | 21.4 | 29.1 | 100.0 |
| MI | 0.0 | 7.8 | 55.4 | 27.1 | 4.8 | 4.8 | 100.0 |
| MN | 0.0 | 15.4 | 76.9 | 7.7 | 0.0 | 0.0 | 100.0 |
| MS | 3.9 | 6.9 | 45.1 | 29.5 | 9.1 | 5.6 | 100.0 |
| MO | 0.4 | 4.8 | 28.0 | 44.9 | 18.5 | 3.5 | 100.0 |
| MT | 0.0 | 9.2 | 34.7 | 41.8 | 8.2 | 6.1 | 100.0 |
| NE | 0.8 | 2.4 | 16.0 | 51.8 | 17.3 | 11.6 | 100.0 |
| NV | 2.1 | 9.5 | 51.5 | 29.9 | 6.2 | 0.8 | 100.0 |
| NH | NA | NA | NA | NA | NA | NA | NA |
| NJ | 0.0 | 1.1 | 18.7 | 45.4 | 14.9 | 19.9 | 100.0 |
| NM | NA | NA | NA | NA | NA | NA | NA |
| NY | 0.6 | 12.2 | 41.6 | 32.5 | 6.8 | 6.4 | 100.0 |
| NC | 0.2 | 1.3 | 31.8 | 40.7 | 15.6 | 10.4 | 100.0 |
| ND | 0.0 | 1.4 | 33.6 | 45.0 | 12.9 | 7.1 | 100.0 |
| OH | 0.0 | 1.7 | 24.0 | 46.3 | 16.2 | 11.9 | 100.0 |
| OK | 0.3 | 3.2 | 43.3 | 46.9 | 5.5 | 0.9 | 100.0 |
| OR | 0.0 | 0.0 | 4.4 | 48.9 | 22.2 | 24.4 | 100.0 |
| PA | 0.0 | 0.0 | 8.8 | 58.2 | 16.7 | 16.3 | 100.0 |
| RI | NA | NA | NA | NA | NA | NA | NA |
| SC | 1.9 | 8.8 | 33.9 | 36.4 | 11.0 | 8.0 | 100.0 |
| SD | 1.7 | 22.7 | 34.7 | 29.0 | 7.4 | 4.5 | 100.0 |
| TN | 0.0 | 1.3 | 23.2 | 48.1 | 15.3 | 12.1 | 100.0 |
| TX | 0.6 | 4.7 | 30.7 | 44.0 | 11.4 | 8.7 | 100.0 |
| UT | 0.0 | 2.2 | 36.1 | 50.0 | 7.0 | 4.8 | 100.0 |
| VT | NA | NA | NA | NA | NA | NA | NA |
| VA | 0.1 | 1.8 | 32.4 | 45.2 | 12.1 | 8.4 | 100.0 |
| WA | 0.0 | 1.7 | 40.0 | 36.5 | 13.8 | 7.9 | 100.0 |
| WV | NA | NA | NA | NA | NA | NA | NA |
| WI | 1.9 | 4.0 | 28.9 | 49.5 | 10.4 | 5.3 | 100.0 |
| WY | 0.0 | 1.0 | 21.4 | 36.9 | 21.4 | 19.4 | 100.0 |
| U.S. Total | 0.6 | 3.7 | 26.0 | 46.1 | 13.8 | 9.8 | 100.0 |

NA = not applicable (state without large state facilities)
 DNF = did not furnish data or insufficient reporting (50% or fewer of residents included)

12 states to less than 10% of all residents in this age range in 5 states.

On June 30, 2004 large state facility residents between 40 and 54 years of age made up 46.1% of all residents, a proportion that increased from 26.2% in 1991, 35.5% in 1996, and 44.2% in 2002. In the same period (1991-2004) the proportion of all residents 40 years or older increased from 39.5% to 69.7% of large state facility residents nationally. The proportion of large state facility residents who are 40 years or older is substantially greater than the 44.3% of the general U.S. population in this age range, but it is clearly being influenced by the same demographic trend, the aging of the "baby boom" generation.

In contrast, children and youth (birth to 21 years), made up about 29.4% of the U.S. population, but only 4.3% of the large state facility population. One reason for the disproportionately low rates of large state facility placements among children and youth are the relatively low overall rates of out-of-home placement of children and youth. In 1997 it was estimated that only 7.7% of all persons with ID/DD in all public and private out-of-home placements were between birth and 21 years (Lakin, Anderson & Prouty, 1998).

A more specific factor with respect to large state facilities is the concerted effort by most states to restrict the admission of children to them. This is particularly evident at the younger ages. In twenty-nine of 49 reporting states there were no large state facility residents younger than 15 years and in 11 additional states children 14 years or younger made up less than 1% of all residents. Nationwide, 20.9% of the population is made up of persons 14 years and younger, but only 0.6% of large state facility populations and 4.3% of all admissions to large state facilities in FY 2004 were persons 14 years and younger. In 1965 the majority of persons admitted to large state facilities were 11 years of age or younger (NIMH, 1966).

Persons 63 and older made up about 14.0% of the U.S. population, and 8% of the large state facility population. A primary reason for the lower proportion of persons 63 years and older in large state facilities than in the general population is the continued high use of nursing facilities for the long-term care of older persons with a primary diagnosis of intellectual disabilities and developmental disabilities. The estimated 4,082 persons 63 years and older in large state facilities in 2004 was considerably less than the 12,200 persons 63 and older with a primary

Table 1.18 Level of Intellectual Disability of Residents of Large State Residential Facilities in 2004

| State | Level of Mental Retardation (%) | | | | Total |
|------------|---------------------------------|----------|--------|----------|-------|
| | Mild + | Moderate | Severe | Profound | |
| AL | 9.5 | 13.6 | 15.1 | 61.8 | 100.0 |
| AK | NA | NA | NA | NA | NA |
| AZ | 1.4 | 8.6 | 37.1 | 52.9 | 100.0 |
| AR | 7.0 | 11.2 | 22.4 | 59.4 | 100.0 |
| CA | 33.7 | 9.4 | 13.3 | 43.7 | 100.0 |
| CO | 40.1 | 20.0 | 7.4 | 32.4 | 100.0 |
| CT | DNF | DNF | DNF | DNF | DNF |
| DE | 3.0 | 3.7 | 14.8 | 78.5 | 100.0 |
| DC | NA | NA | NA | NA | NA |
| FL | 36.8 | 13.2 | 11.2 | 38.7 | 100.0 |
| GA | 5.4 | 10.4 | 16.2 | 68.0 | 100.0 |
| HI | NA | NA | NA | NA | NA |
| ID | DNF | DNF | DNF | DNF | DNF |
| IL | 10.9 | 13.0 | 21.5 | 54.6 | 100.0 |
| IN | 47.1 | 21.3 | 6.0 | 25.7 | 100.0 |
| IA | 24.1 | 17.3 | 17.8 | 40.8 | 100.0 |
| KS | 15.1 | 11.0 | 14.0 | 59.9 | 100.0 |
| KY | 7.2 | 12.9 | 23.0 | 56.8 | 100.0 |
| LA | 13.6 | 14.7 | 13.2 | 58.6 | 100.0 |
| ME | NA | NA | NA | NA | NA |
| MD | 11.4 | 6.5 | 15.0 | 67.1 | 100.0 |
| MA | 15.7 | 16.1 | 20.9 | 47.3 | 100.0 |
| MI | 45.8 | 12.7 | 18.1 | 23.5 | 100.0 |
| MN | 76.9 | 19.2 | 3.8 | 0.0 | 100.0 |
| MS | 9.1 | 13.8 | 13.6 | 63.5 | 100.0 |
| MO | DNF | DNF | DNF | DNF | DNF |
| MT | 34.7 | 23.5 | 5.1 | 36.7 | 100.0 |
| NE | 10.1 | 10.1 | 8.7 | 71.0 | 100.0 |
| NV | 24.0 | 14.6 | 30.1 | 31.3 | 100.0 |
| NH | NA | NA | NA | NA | NA |
| NJ | 10.3 | 8.8 | 15.8 | 65.1 | 100.0 |
| NM | NA | NA | NA | NA | NA |
| NY | 45.5 | 13.2 | 11.9 | 29.4 | 100.0 |
| NC | 1.9 | 6.6 | 14.0 | 77.6 | 100.0 |
| ND | 24.3 | 10.0 | 11.4 | 54.3 | 100.0 |
| OH | 3.0 | 17.9 | 19.1 | 60.0 | 100.0 |
| OK | 4.8 | 3.9 | 22.3 | 69.0 | 100.0 |
| OR | 2.2 | 2.2 | 6.7 | 88.9 | 100.0 |
| PA | 3.0 | 5.9 | 15.6 | 75.5 | 100.0 |
| RJ | NA | NA | NA | NA | NA |
| SC | 4.3 | 7.2 | 15.7 | 72.8 | 100.0 |
| SD | 48.3 | 14.8 | 9.1 | 27.8 | 100.0 |
| TN | 1.8 | 3.3 | 8.3 | 86.7 | 100.0 |
| TX | 11.7 | 10.8 | 19.9 | 57.7 | 100.0 |
| UT | 10.4 | 3.5 | 9.6 | 76.5 | 100.0 |
| VT | NA | NA | NA | NA | NA |
| VA | 17.3 | 10.2 | 19.9 | 52.6 | 100.0 |
| WA | 3.5 | 8.2 | 23.6 | 64.7 | 100.0 |
| WV | NA | NA | NA | NA | NA |
| WI | 3.2 | 5.3 | 17.9 | 73.7 | 100.0 |
| WY | 1.0 | 1.0 | 37.8 | 60.2 | 100.0 |
| U.S. Total | 10.2 | 10.5 | 17.7 | 61.6 | 100.0 |

NA= not applicable (state without large state facilities)
DNF= data not furnished or insufficient reporting (60% or fewer of residents included)

diagnosis of intellectual disabilities in nursing facilities based on the total 2004 nursing facility residents in this survey and the estimated 37% of nursing home residents with a primary diagnosis of intellectual disability who were 63 years or older as estimated in the 1985 National Nursing Home Survey (Lakin, Hill, and Anderson, 1991).

Level of Intellectual Disability

Table 1.18 presents the state-by-state distributions of residents of large state facilities by reported level of intellectual disability. Thirty-nine states are reported; 8 states are not included because they operated no large state facilities at the time of this survey. In one state the large state facilities reporting this statistic had less than 60% of the total state facility population and was excluded.

In Table 1.18 persons reported not to have intellectual disabilities have been included in the "mild" intellectual disabilities group. Nationally 61.6% of large state facility residents were indicated to have profound intellectual disabilities. In all but 12 states a majority of the large state facility residents were reported to have profound intellectual disabilities.

Nationwide, 20.7% of residents were reported to have mild or moderate intellectual disabilities. In 16 states, persons with mild or moderate intellectual disabilities made up more than a quarter of large state facility populations; in 9 states less than 10%. As shown in Table 1.14 the proportion of residents with mild intellectual disabilities has increased modestly nationwide in recent years, related in part to the increasing proportion of residents indicated to have psychiatric and behavioral disorders. In 2004 62.2% of large state facility residents were reported to have psychiatric disorders and 52.3% to have behavioral disorders, an increase from 31.0% and 45.7% respectively since 1996.

Selected Additional Conditions

Table 1.19 presents the reported prevalence of selected secondary conditions of large state facility residents.

Blind. Nationwide, 12.4% of large state facility residents were reported to be functionally blind in June 2004 (defined as having little or no useful vision). This compares with 12.6% in 1991, 15.3% in 1996, and 13.5% in 2002. Fourteen states reported 15% or more residents to be functionally blind.

Deaf. Nationally, 6.4% of large state facility residents were reported to be functionally deaf (having little or no useful hearing). This compares with 5.6% in 1991, 7.4% in 1996 and 6.6% in 2002. Seven states reported more than 10% of residents being functionally deaf.

Epilepsy. Nationwide, 42.7% of large state facility residents were reported to have epilepsy. This compares with 44.6% in 1991, 46.1% in 1996, and 45.0% in 2002. Thirty of 40 states reported prevalence rates for seizure disorders among large state facility residents of between 30% and 60%.

Cerebral Palsy. Nationwide, 18.0% of large state facility residents were indicated to have cerebral palsy. This compares to a reported rate of 21.6% in 1991, 22.6% in 1996, and 19.4% in 2002. The reported prevalence of cerebral palsy varied from state to state. In 13 of 39 reported states a quarter or more of large state facility residents were reported to have cerebral palsy.

Behavior Disorder. Individual large state facilities were asked to report the number of their residents with behavior disorders. *Behavior disorder* was defined simply as "behavior that was sufficiently problematic as to require special staff attention." The absence of a definition expressed in behavioral terms of frequency or severity may account for some of the deviation among states from the national average of 52.3%. In 11 states, 60% or more of large state facility residents were reported to have behavior disorders; in 9 states less than 40% of the large state facility residents were reported to have behavioral disorders. The reported prevalence of behavioral disorders has increased from 40.7% to 52.3% between 1987 and 2004.

Psychiatric Condition. Individual facilities were also asked how many of their residents have *psychiatric disorders* defined as "requiring the attention of psychiatric personnel." Nationwide, 47.9% of large state facility residents were reported to be receiving psychiatric attention for psychiatric conditions. This statistic was first collected in 1994 when a prevalence of 30.6% was reported. It has steadily increased in each survey since: 31.0% in 1996, 34.3% in 1998, 42.0% in 2000, 45.7% in 2002, and 47.9% in 2004. Twenty-seven of 40 reporting states reported rates between 35% and 65%.

Multiple Conditions. In all 62.2% of large state facility residents were reported to have two or more of the above conditions in addition to intellectual disabilities. Twenty-five states reported 60% or

Table 1.19 Selected Additional Conditions of Residents of Large Facilities by State on June 30, 2004

| State | Blind (%) | Deaf (%) | Epilepsy (%) | Cerebral Palsy (%) | Behavioral Disorder (%) | Two or More Conditions (%) | Psychiatric Disorder (%) | Meds for Mood & Behav. (%) |
|------------|-----------|----------|--------------|--------------------|-------------------------|----------------------------|--------------------------|----------------------------|
| AL | 14.6 | 5.0 | 33.2 | 10.1 | 81.9 | 48.2 | 46.2 | 44.2 |
| AK | NA | NA | NA | NA | NA | NA | NA | NA |
| AZ | 12.9 | 14.3 | 54.3 | 29.3 | 45.7 | 40.7 | 82.9 | 40.7 |
| AR | 7.9 | 4.8 | 32.3 | 22.8 | 52.3 | 60.4 | 51.7 | 59.3 |
| CA | 18.0 | 7.1 | 41.6 | 25.5 | 48.8 | 62.4 | 62.0 | 67.2 |
| CO | 6.0 | 4.1 | 26.1 | DNF | 73.1 | 69.4 | 5.6 | 69.4 |
| CT | DNF | DNF | DNF | DNF | DNF | DNF | DNF | DNF |
| DE | 19.3 | 1.5 | 59.3 | 43.0 | 11.1 | 42.2 | 48.9 | 23.0 |
| DC | NA | NA | NA | NA | NA | NA | NA | NA |
| FL | 6.5 | 7.4 | 26.1 | 4.9 | 43.8 | 36.3 | 37.8 | 36.8 |
| GA | 21.9 | 8.9 | 55.9 | 5.6 | 59.1 | 19.1 | 72.3 | 37.6 |
| HI | NA | NA | NA | NA | NA | NA | NA | NA |
| ID | DNF | DNF | DNF | DNF | DNF | DNF | DNF | DNF |
| IL | 11.4 | 8.1 | 39.7 | 14.7 | 61.0 | 47.4 | 61.9 | 42.6 |
| IN | 4.0 | 1.0 | 26.4 | 9.4 | 52.2 | 74.7 | 69.7 | 71.8 |
| IA | 6.9 | 2.1 | 36.6 | 4.3 | 42.8 | 80.1 | 71.0 | 65.3 |
| KS | 7.0 | 1.4 | 51.0 | 40.4 | 58.6 | 22.1 | 55.7 | 22.4 |
| KY | 14.2 | 4.4 | 51.6 | 12.9 | 55.4 | 49.1 | 88.1 | 45.1 |
| LA | 9.9 | 5.4 | 38.4 | 20.6 | 37.2 | 35.4 | 66.0 | 36.6 |
| ME | NA | NA | NA | NA | NA | NA | NA | NA |
| MD | 23.3 | 11.6 | 49.6 | 26.4 | 12.1 | 33.0 | 85.9 | DNF |
| MA | 12.8 | 6.2 | 49.2 | 15.6 | 52.4 | 51.6 | 67.0 | 50.9 |
| MI | 6.6 | 7.8 | 38.6 | 6.6 | 89.8 | 85.5 | 91.0 | 82.5 |
| MN | 0.0 | 3.8 | 19.2 | 0.0 | 100.0 | 96.2 | 100.0 | 100.0 |
| MS | 6.6 | 4.8 | 23.9 | 13.2 | 36.2 | 37.7 | 21.8 | 33.2 |
| MO | 7.9 | 3.5 | 29.1 | 12.0 | 73.5 | 41.9 | 36.9 | 67.2 |
| MT | 7.1 | 4.1 | 32.7 | 3.1 | 55.1 | 44.9 | 89.8 | 53.1 |
| NE | 15.1 | 4.3 | 52.2 | 13.8 | 42.4 | 43.0 | DNF | 37.6 |
| NV | 6.3 | 5.8 | 49.3 | 7.2 | 48.4 | 71.3 | 82.9 | 87.1 |
| NH | NA | NA | NA | NA | NA | NA | NA | NA |
| NJ | 11.4 | 11.2 | 40.7 | 34.2 | 45.1 | 41.7 | 37.0 | 44.1 |
| NM | NA | NA | NA | NA | NA | NA | NA | NA |
| NY | 8.4 | 4.1 | 27.6 | 7.8 | 62.9 | 63.9 | 64.9 | 74.1 |
| NC | 16.1 | 4.3 | 56.2 | 26.7 | 39.4 | 29.9 | 71.1 | 38.6 |
| ND | 7.9 | 10.0 | 40.0 | 27.1 | 77.9 | 63.6 | 55.7 | 63.6 |
| OH | 9.3 | 3.5 | 46.0 | 9.3 | 56.1 | 52.4 | 60.2 | 52.4 |
| OK | 12.9 | 13.5 | 54.1 | 29.8 | 27.9 | 26.6 | 75.7 | 40.9 |
| OR | 6.8 | 2.3 | 31.8 | 2.3 | 79.5 | 56.8 | 4.5 | 56.8 |
| PA | 16.6 | 4.3 | 55.2 | 29.3 | 37.1 | 45.1 | 83.5 | 42.5 |
| RI | NA | NA | NA | NA | NA | NA | NA | NA |
| SC | 17.2 | 3.8 | 55.8 | 15.4 | 52.1 | 41.0 | 40.0 | 39.3 |
| SD | 1.1 | 0.6 | 30.7 | 5.1 | 100.0 | 96.6 | 100.0 | 92.6 |
| TN | 15.2 | 3.7 | 58.2 | 55.3 | 23.1 | 42.0 | 85.3 | 20.4 |
| TX | 15.7 | 6.2 | 47.2 | 20.5 | 53.0 | 51.5 | 66.3 | 52.7 |
| UT | 28.3 | 15.2 | 63.5 | 27.8 | 100.0 | 58.7 | 87.0 | 58.7 |
| VT | NA | NA | NA | NA | NA | NA | NA | NA |
| VA | 16.7 | 12.2 | 50.1 | 23.2 | 62.2 | 39.9 | 64.3 | 41.4 |
| WA | 13.9 | 5.8 | 48.9 | 12.0 | 58.0 | 44.6 | 59.4 | 44.3 |
| WV | NA | NA | NA | NA | NA | NA | NA | NA |
| WI | 29.7 | 4.7 | 66.0 | 42.9 | 49.6 | 46.4 | 82.9 | 42.5 |
| WY | 15.5 | 7.8 | 1.9 | 1.0 | 30.1 | 29.1 | 100.0 | 31.1 |
| U.S. Total | 12.4 | 6.4 | 42.7 | 18.0 | 52.3 | 47.9 | 62.2 | 50.0 |

NA = not applicable (state without large state facilities)
 DNF = data not furnished or insufficient reporting (50% or fewer of residents included)

more of their of large state facility residents as having multiple conditions.

Medications for Mood, Anxiety, or Behavior. Half (50.0%) of all residents of large state facilities are reported to receive prescribed medications for mood, anxiety or behavior problems. Rates of medication fell between 35% and 65% in 25 of 39 reporting states.

Selected Functional Assistance Needs of Residents

Table 1.20 presents selected functional limitations of residents of large state ID/DD facilities.

Walking. Nationwide, 36.8% of residents of large state facilities were reported to need assistance or supervision in walking. This was relatively similar to the 32.4% reported in 1991, 35.7% in 1996, and 37.0% in 2002. Reported rates varied from 0.0% in Minnesota to more than half of all residents in 10 states.

Dressing. Nationwide, 59.8% of large state facilities residents were reported to need assistance or supervision in dressing. This compares with 61.1% in 1991, 66.1% in 1996, and 62.6% in 2002. In 18 states two-thirds or more of large state facility residents were reported to need assistance dressing. Only ten states reported less than 50% of their large state facility residents in need of assistance or supervision in dressing.

Eating. Nationwide, 51.0% of large state facility residents were reported to need assistance or supervision feeding themselves. This compares with 50.9% reported to need assistance in feeding themselves in 1996 and 51.4% in 2002. Sixteen states reported that 60% or more of their large state facility residents needed help or supervision in eating while 10 states indicated that 40% or less of their large state facility populations needed assistance or supervision in eating.

Understanding. Nationwide, 30.0% of large public facility residents were reported not to be able to understand simple verbal requests. States ranged from less than 20% of residents not understanding simple requests in 12 states to more than 50% in 6 states.

Communicating. A total 54.9% of large state facility residents were reported to be unable to communicate their basic desires verbally. This compares with 59.4% in 1996, and 58.1% in 2002. Fourteen states reported more than two-thirds of their large state

facility residents could not communicate verbally; 6 states reported less than 50% of their large state facility residents could not communicate their basic desires verbally.

Toileting. Nationwide, 53.6% of large state facility residents were reported to need assistance or supervision with toileting. This was an increase from the 46.6% reported in 1987, but slightly less than the 57.0% reported in 1996 and the 55.9% reported in 2000. Sixteen states reported more than two-thirds of large state facility residents needing assistance with toileting; 10 states reported less than 40% of large state facility residents needing assistance or supervision with toileting.

Residents in Movement

New Admissions by Age and Level of Intellectual Disability

Table 1.21 presents the distribution of persons newly admitted to large state facilities in FY 2004 by their age and level of intellectual disability. Data reported in Table 1.21 were supplied by large state facilities with 87.4% of reported admissions. As shown in Table 1.20 persons newly admitted to large state facilities in FY 2004 presented a different profile from the general large state facility population on June 30, 2004. In general they were considerably younger and less severely cognitively impaired than the general population. For example, 4.3% of the total large state facility population was 0-21 years old as compared with 31.8% of the new admissions. While 3.7% of the general large state facility population was made up of persons 15-21 years, 27.3% of new admissions were in this age group. In contrast, while persons 40 years and older made up 69.7% of the large state facility populations, they made only 30.0% of the new admissions. Of course, the relatively higher proportion of young people in the new admission category as compared with general facility population reflects the fact that most people entering residential programs do so in adolescence or young adulthood. In general, between 1987 and 2004, the proportion of children and youth (0-21 years) among new admissions has not changed appreciably, ranging between 31%-35%. Newly admitted middle aged and older residents (40 years and older) have also remained quite stable between about 23.0% and 30.0% of all new admissions.

Newly admitted large state facility residents in FY 2004 were much more likely to have mild intellectual disabilities or and considerably less likely to have profound intellectual disabilities than the

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ABUSE AND NEGLECT OF PEOPLE WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES IN COMMUNITY SETTINGS

Source:
VOR, Rev. February 2006



***Speaking out
for people with mental retardation***

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Rev. Feb. 2006

**Media coverage highlighting the increasing need for
more effective federal and state protections in the ever-expanding community
system of care for people with mental retardation**

**Call to Action
to State and Federal Policymakers**

Any realistic examination of the nationwide community services system reveals glaring weaknesses in the capability of current services systems to deliver high quality supports to individuals with mental retardation and developmental disabilities.¹ This truth is borne out in media headlines every day across the country.

The increased emphasis on the use of very small living arrangements has caused the number of sites to increase dramatically and become diffused throughout communities. There is little doubt that the explosion in the number of these small, community-based residential sites is posing substantially greater quality management and system infrastructure challenges for states and local developmental disabilities authorities.

See http://www.vor.net/abuse_neglect.htm for an extensive bibliography of state audits, peer-reviewed studies and media investigative series. This 28 page resource includes 74 listings from 32 states and 7 national articles detailing systemic community quality of care concerns.

State officials are left, seemingly, with no easy solutions. When faced with mounting costs, increased needs, and relentless pressure (advocacy and legal) from advocates who demand community placement for all people with disabilities, states often forget the most important part of the equation: Individuals with mental retardation and developmental disabilities.

It is time that States step back, carefully consider the existing quality of its community service system and pose such questions as, "How are those people now in the system being served?," "How much money is needed to improve the system for current and future users?," and "Are the state's monitoring and oversight mechanisms effective to ensure continued quality improvement?"

State developmental disabilities officials must ensure the highest quality of life and care for people in their charge. Lessons learned from other states — including what not to do — can help lead the way.

Voice of the Retarded is the only national organization supporting an array of quality services options, including own-home, other community-based services and supports, and Intermediate Care Facilities for People with Mental Retardation (ICFs/MR).

¹Developmental Disabilities Quality Coalition.

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THE OLMSTEAD DECISION



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Olmstead requires choice of residential settings

The Supreme Court, in its Olmstead ruling, recognized the need for a range of services which respond to the varied and unique needs of the entire disability community:

- (1) Unjustified institutionalization is discrimination based on disability.
119 S. Ct. 2176, 2185 (1999).
- (2) The Supreme Court held that community placement is only required and appropriate (i.e., institutionalization is unjustified), when –
 - “(a) the State’s treatment professionals have determined that community placement is appropriate;
 - (b) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and
 - (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.” 119 S. Ct. at 2181.
- (3) A majority of Justices in Olmstead recognized an ongoing role for publicly and privately-operated institutions: “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.” 119 S. Ct. at 2187.
- (4) A plurality of Justices noted: “As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... ‘Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution’[quoting VOR’s *Amici Curiae* brief].” 119 S. Ct. at 2189.
- (5) Justice Kennedy noted in his concurring opinion, “It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.” 119 S. Ct. at 2191.

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**THE MYTH OF AN “INSTITUTIONAL BIAS” IN
MEDICAID FOR PERSONS WITH MENTAL
RETARDATION AND DEVELOPMENTAL
DISABILITIES**

The Myth of an "Institutional Bias" in Medicaid for Persons with Mental Retardation and Developmental Disabilities

Often it is alleged that 70% of all Medicaid long-term care dollars pay for institutional care. Globally, this is true. Specifically, related to the mental retardation and developmental disabilities (MR/DD) population, it is not true. The Medicaid program for long-term care spends more dollars and supports more people with MR/DD in the community, including in the Home and Community Based Services (HCBS) waiver program, than for those in Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR).

What then, is the basis for the 70% myth? The answer lies in the fact that the Medicaid program covers more than people with MR/DD; it also covers people who reside in nursing facilities (NF), most of whom are elderly. The so-called institutional bias in the numbers occurs because Medicaid defines "institutional care" to include all Medicaid-eligible populations, the vast majority of whom reside in NFs. The facts are far different when one separates the MR/DD and elderly populations.

The "institutional bias" of Medicaid myth as applied to services for persons with MR/DD can have dangerous consequences for our most fragile citizens. For example, proposals such as Money Follows the Person (MFP) and the Medicaid Attendant Services and Supports Act (MiCASSA) are motivated by a desire to "rebalance" the system by increasing community supports at the expense of "institutional" (including ICF/MR) options. In this process, ICF/MR care may become uneconomical and extinct, risking the health, safety and very lives of people with severe and profound mental retardation if these facilities close. While there is a great need to expand community-based options, it should not be done at the expense of another Medicaid population. Focus on expansion must address the areas of greatest need for people with MR/DD – the provision of quality community options, including ready access to health care services, and helping those on waiting lists for services.

Here are the facts about the Medicaid program:

- Nearly 70% of the Medicaid funds for long-term care (for both people with MR/DD and the elderly) are spent for services provided in "institutional" settings. However, only 20% of this funding is for people with MR/DD who reside in ICFs/MR (Table 1).
- When one looks at only Medicaid expenditures for persons with MR/DD who reside in ICFs/MR and in HCBS, it turns out that Medicaid spends more for community services (55%) than for institutional care (45%). (Table 2). Note: NF expenditures for MR/DD residents, who are only 2.4% of the NF population, are excluded from Table 2 because reliable data could not be located.

Table 1²

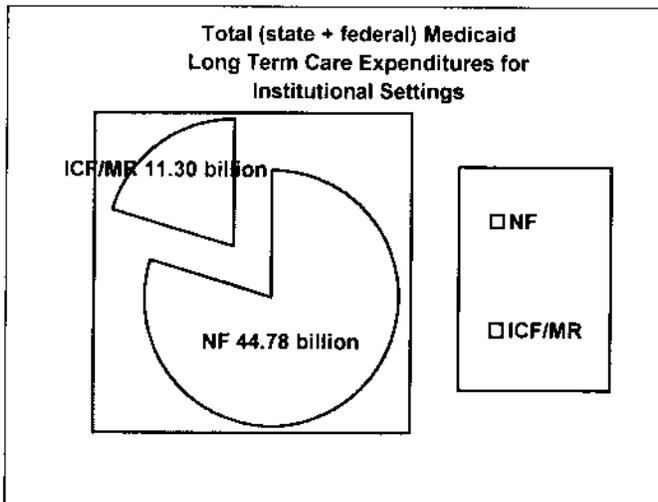
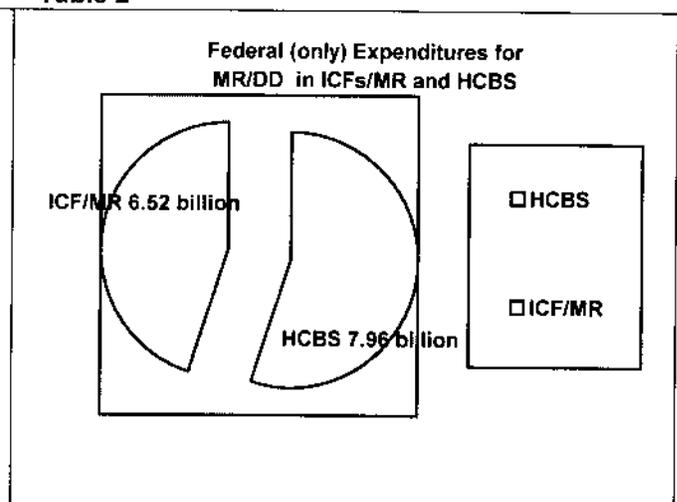


Table 2³



- HCBS recipients comprise 74% of MR/DD residents in Medicaid-funded long-term care settings. ICFs/MR recipients make up just 20% and the remaining 6% reside in nursing facilities (Table 3).
- Medicaid-funded HCBS and other community residences, as compared to ICFs/MR, comprise 95% of the residential placement options for persons with MR/DD (Table 4). These figures exclude individuals with MR/DD receiving services in the family home or their own home, which represents an additional 500,004⁴ people receiving non-residential community-based services, although it is unclear what percentage of this amount is Medicaid-supported.

Table 3⁵

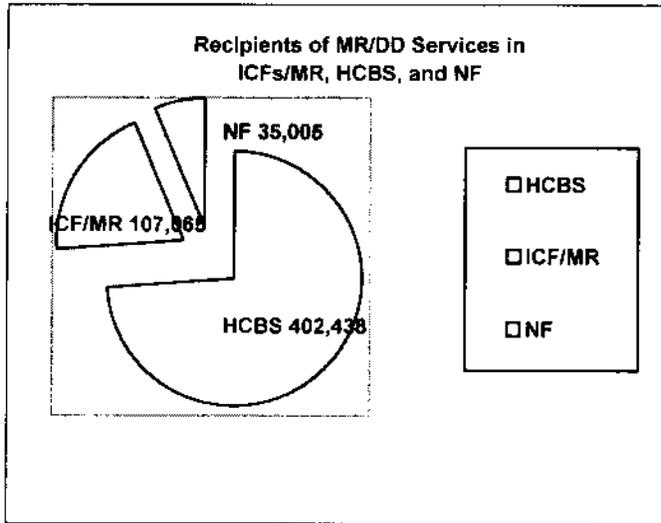
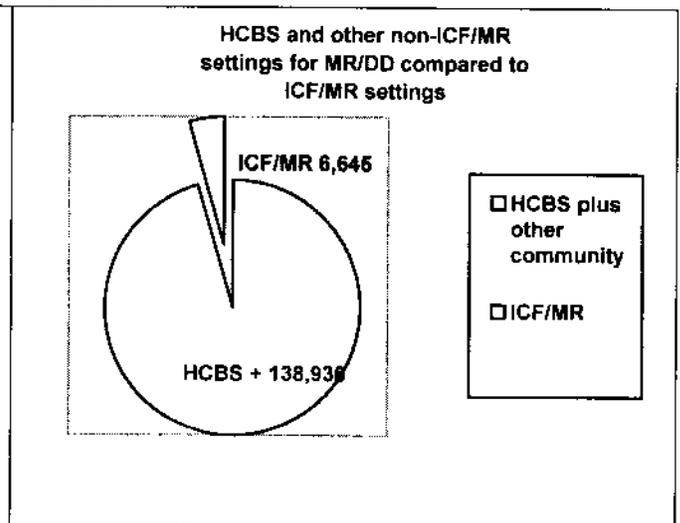


Table 4⁶



- 79.7% of individuals who reside in ICFs/MR have severe and profound mental retardation and require 24-hour around-the-clock care for their safety. Nearly half (47%) of these same residents have two or more additional conditions, and nearly all need help walking, toileting, eating, dressing and/or communicating verbally. By sharp contrast, the vast majority of people with MR/DD who reside in the community are far higher functioning individuals with little or no need for intensive care services.
- A 2003 peer-reviewed study by Kevin Walsh, Ph.D., concluded that "From the studies reviewed here, it is clear that large savings are not possible within the field of developmental disabilities by shifting from institutional to community placements." Thus, if more funds were spent to move people from ICFs/MR, little or no money would be saved, unless the quality of the lives of the clients were reduced through lesser quality care and services.

¹ Trend in the cost of Operating a Nursing Home: Analysis of Medicare Cost Reports for Skilled Nursing Facilities, Health Services Research and Evaluation, American Health Care Association (January 26, 2004)(Total number of residents in nursing facilities (2003) was 1,450,319, including 35,005 residents with MR/DD (see Table 3)).

² Steve Gold, "Medicaid 2003 Expenditures," Information Bulletin #68 (May 26, 2004).

³ Residential Settings for Persons with ID/DD served by State and Nonstate agencies on June 30, 2003. In R. W. Prouty, Gary Smith & K.C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2003*, University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, <http://rtc.umn.edu/risp03/risp03.pdf>, Tables 3.4 (p. 66) and 3.7 (p. 73). *The federal government "match" is 56.85% (average) of state Medicaid spending.*

⁴ *Id.*, Table 2.9 (p. 45).

⁵ *Id.*, Tables 3.12 (p. 83), 3.13 (p. 84), and 3.2 (p.60).

⁶ *Id.*, Tables 2.1 (p.34) and 3.1 (p. 58) (figure for HCBS plus other community settings derived by taking the total state and nonstate residential settings for persons with MR/DD, from Table 2.1, and subtracting total ICF/MR settings from Table 3.1).

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COST COMPARISONS OF COMMUNITY AND INSTITUTIONAL RESIDENTIAL SETTINGS: HISTORICAL REVIEW OF SELECTED RESEARCH

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Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research

Kevin K. Walsh, Theodore A. Kastner, and Regina Gentlesk Green

Abstract

A review of the literature on cost comparisons between community settings and institutions for persons with mental retardation and developmental disabilities was conducted. We selected literature for review that was published in peer-reviewed journals and had either been cited in the area of cost comparisons or provided a novel approach to the area. Methodological problems were identified in most studies reviewed, although recent research employing multivariate methods promises to bring clarity to this research area. Findings do not support the unqualified position that community settings are less expensive than are institutions and suggest that staffing issues play a major role in any cost differences that are identified. Implications are discussed in light of the findings.

The significant growth of community-based services has given rise to a dramatic shift in how services, especially residential services, are provided to people with mental retardation. As community-based services have expanded relative to institutions, aspects of costs, efficiency, and outcomes have grown in importance to practitioners, policy makers, and researchers (Braddock, Hemp, & Howes, 1986, 1987; Braddock, Hemp, & Fujiura, 1987; Campbell & Heal, 1995; Felce, 1994; Harrington & Swan, 1990; Mitchell, Braddock, & Hemp, 1990; Murphy & Dattel, 1976; Nerney & Conley, 1992; Rhoades & Altman, 2001; Stancliffe & Lakin, 1998). Despite the reduction in the number and size of large facilities that accompanied the increase in community-based residential services, large facilities are still with us. Tracking of facility trends shows that there are still more than 250 facilities nationwide with 16 or more beds serving nearly 48,000 individuals, 80% of whom are classified as having either severe or profound mental retardation (Prouty, Smith, & Lakin, 2001; Lakin, Prouty, Polister, & Kwak, 2001; Smith, Polister, Prouty, Bruininks, & Lakin, 2001). According to Polister, Smith, Prouty, and Lakin (2001), of the state-run facilities with 16 or more beds, 113 of them (nearly 60%) serve 150 or more individuals.

Several factors underlie the continued use of large facilities, including the institutional bias produced by the entitlements in federal Medicaid programs along with the pace of community expansion and the characteristics of the individuals themselves. For example, although community residential settings with 15 or fewer residents now number nearly 120,000 nationwide, waiting lists continue to grow and are a concern for policy makers and service providers. In studies of waiting lists, Davis, Abeson, and Lloyd (1997) and Lakin (1996) found between 52,000 and 87,000 individuals waiting for residential services, and nearly 65,000 were waiting for day programs. Overall, Davis et al. reported that 218,186 people were waiting for any type of services. Emerson (1999) has identified the same problem in the United Kingdom. Thus, the demand for community services for people with mental retardation and related developmental disabilities (MR/DD) has grown faster than the capacity of states to expand or create new community-based services.

The characteristics of individuals remaining in institutional facilities has also changed. Individuals still in institutions tend to be older and have more problems in daily living skills and in walking independently (Prouty et al., 2001). Although challenging behaviors are observed in both institutional

and community settings, more individuals remaining in large settings present challenging behaviors (Borthwick-Duffy, 1994; Bruininks, Olson, Larson, & Lakin, 1994). On average, about 47% of residents of large state facilities are reported to have behavior disorders, a statistic that has slowly increased since the late 1980s, from around 40%.

Although many have argued that institutions cost more than community settings (e.g., Heal, 1987), others have reported minimal cost differences (e.g., Schalock & Fredericks, 1990) or differences that favor institutions (e.g., Emerson et al., 2000). These different outcomes arise from the inherent complexities of research in this area, which is characterized by a heterogeneous population, complex funding strategies, methodological challenges, and substantial variability (cf. Butterfield, 1987).

Because a diversity of viewpoints exists, and because both settings are likely to coexist for some time, it is reasonable to review research in which investigators have examined the costs of these service models. This research area is rich in complexity and, although policy reports on costs and expenditures have appeared (e.g., Braddock, Fujiura, Hemp, Mitchell, & Bachelder, 1991; Braddock, Hemp, & Fujiura, 1987; Harrington & Swan, 1990; LeBlanc, Tonner, & Harrington, 2000), few reviewers of the cost literature have critically examined methodological elements of the available cost-comparison studies. This has added to the difficulty in drawing firm conclusions.

Although recent literature in this area has, to some extent, included evaluation of outcomes in addition to service costs, our primary focus in this article is on research in which costs were compared. This is not to denigrate the importance of outcomes; rather, our focus reflects the limitations of a single paper as well as the reality that although government officials and service elements typically desire to take quality and outcomes into account when planning programs, legislators often respond more directly to cost issues in funding decisions.

Considerations in Comparing Costs

Sources of Funds

Although services and supports for people with MR/DD are administered by states, the funds to pay for them are not limited to state funds; funds also come from local (e.g., county) and federal sources. The federal government plays a substantial role in states through the Medicaid Intermediate Care Fa-

cilities for the Mentally Retarded (ICF/MR) program and the Home and Community-Based Services (HCBS) Waiver program (Harrington & Swan, 1990; LeBlanc et al., 2000; Müller, Ramsland, & Harrington, 1999). Services for people with MR/DD in states are funded, to a large extent, through these two programs, which provide matching funds, with the proportions of federal and state contributions varying across the states (Braddock & Fujiura, 1987; Braddock & Hemp 1997; Braddock, Hemp, & Fujiura, 1987; LeBlanc et al., 2000; Lutsky, Alexih, Duffy, & Neill, 2000; Smith & Gettings, 1996). Currently, all 50 states have at least one active ICF/MR facility (Centers for Medicare & Medicaid Services, 2001), although not all ICF/MR facilities are large (i.e., institutions). Most large state-run facilities participate in the ICF/MR program, although there are large private ICFs/MR as well.

The HCBS Waiver program aids states in providing habilitative and other supports in community settings. Eiken and Burwell (2001) reported that

about three-fourths of (federal) Waiver expenditures are used to purchase long term care supports for persons with mental retardation and other developmental disabilities. In FY 2000, about \$9.3 billion of the total \$12.4 billion spent for HCBS Waiver services was targeted to persons with MR/DD.

This amount nearly equaled the \$9.9 billion spent on ICF/MR services in the same year. Since 1995, the average annual growth rate of HCBS Waiver services for people with MR/DD has been over 17%, whereas spending for the ICF/MR program has increased, on average, by less than 1%.

Cost Shifting

Results of early unpublished studies suggested that large facilities were up to 2.5 times as expensive as community facilities (e.g., Ashbaugh & Allard, 1983; Wieck & Bruininks, 1980). However, such conclusions are no longer valid because the analyses took place prior to the full operation of the HCBS Waiver program. Given the differences in the ICF/MR program and the HCBS Waiver program, there is the potential for costs to be *shifted* in complex ways. For example, whereas a placement in a large ICF/MR facility involves both state and federal funds, in varying proportions and at different levels across the states, not all community placements receive federal funds. Although some community-based placements are funded by both federal and state funds (e.g., under the HCBS Waiver), other services and supports are funded

solely by state funds, or are funded by complex combinations of personal/ private funds (including "entitlement" funds under Social Security) along with state funding.

In addition, the federal component of funding under both Medicaid programs varies from state to state, and for the HCBS Waiver, it varies based on what is contained in each state's Waiver agreement with the Centers for Medicare and Medicaid Services (CMS). Consequently, as fewer individuals are served in ICF/MR settings and more receive HCBS services, certain costs may be shifted to other Medicaid programs, or other state funds. According to Lutsky et al. (2001):

Pet recipient Waiver spending fails to capture actual spending on Waiver recipients because it only accounts for a portion of their expenditures. HCBS Waiver recipients typically have some of their care, most notably acute care, home health, personal care, targeted case management, and adult day care, funded from the regular Medicaid program. (p. 8)

Cost Variation

Costs vary both *between* and *within* agencies and service systems, based on complex factors that affect them in several ways. Very similar services may vary widely in costs based on geography (e.g., urban vs. rural), unionization of staff, availability of professional staff, staff levels and ratios, ownership status (i.e., public vs. private), and other local factors in addition to characteristics of the consumers served. Such cost variation has been a consistent finding in the literature (Campbell & Heal, 1995; Mitchell, et al., 1990; Nerney & Conley, 1992).

Service costs also change over time as dynamic service systems constantly alter their complexion. For example, costs per resident in an institutional facility tend to rise when the most capable residents are removed and placed in community-based facilities. In addition, cost variation is typical both within and between service facility types. For example, in a study comparing costs in the United Kingdom, Hatton, Emerson, Robertson, Henderson, and Cooper (1995) reported average per person cost variations of as much as \$20,000 between institutional placements and specialized units *within* institutions and the same amount of variation among regular group homes. This phenomenon has also regularly appeared in the literature in America (e.g., Jones, Conroy, Feinstein, & Lemanowicz, 1984; Lakin, Polister, Prouty, & Smith, 2001; Nerney & Conley, 1992).

Staffing

Staffing levels and ratios have been identified as one of the major sources of cost differences across settings (Campbell & Heal, 1995; Felce, 1994). In addition to variability in staffing ratios across settings, there are clear-cut differences in salary and benefit levels. For example, public employees typically have richer compensation packages, and there may also be increased costs associated with the availability of professional and therapy staff. In short, staffing is not a stable variable with wide variability in compensation levels across settings and high rates of turnover (e.g., Braddock & Mitchell, 1992). Staffing levels and costs associated with staff, including recruitment and retention, vary depending on the needs and conditions, and the regulations in a particular setting (Larson, Hewitt, & Anderson, 1999). Therefore, costs associated with staff will prove to be a critical variable in all service models in the future.

Case Mix and Functioning Level

As community services expanded during the past quarter century, the average functioning level of individuals remaining in institutional facilities declined while, in general, their average age increased compared to the general population served by state agencies. These changes have taken place because fewer individuals overall were placed in institutional facilities, and special efforts were made to restrict the institutionalization of children (Lakin, Anderson, & Prouty, 1998). In addition, individuals with more skills and abilities are typically placed in community settings before individuals with more complex needs.

Thus, there are now stark differences in the populations served in community settings and those remaining in larger settings, typically public ICF/MR facilities. With respect to comparisons between these two groups, whether on costs, functional skills, quality of life issues, and so forth, population differences must be considered. In research terms, this process is known as *correcting for case mix* or *controlling for client mix* (Mitchell et al., 1990) and assures comparability based on characteristics of consumers. The importance of correcting for the severity of those served is underscored by Felce and his colleagues (Felce, Lowe, Beecham, & Hallam, 2000), who concluded that "costs of residential services in general have been found to depend on case mix, with the mediating variable being level of staff per resident" (p. 309). Taken together, the factors

of funding source, cost variation, staffing, and case mix are well-known and central to the cost-comparison literature. We now turn to a selective review of the literature showing how the research has addressed these and other issues in studies of service system costs in the MR/DD field.

Literature Selection

To show how the phenomena described above can affect conclusions about costs, we present a historical review of cost-comparison literature, highlighting studies that have gained prominence or address the issues raised herein. A comprehensive literature search was conducted using standard search strategies (Nerney, 2000) in several computerized databases (e.g., Medline, CINAHL, ClinPSYCH, PsychSCAN LD/MR) using keywords (e.g., *mental retardation, developmental disabilities, ICF/MR, costs, community, institution*) directly or in combinations to create Boolean searches. Two project members conducted literature searches using selection criteria requiring that identified documents (a) covered the MR/DD population; (b) included cost data or cost-related policy analysis; (c) were published or available since 1975; (d) were not case studies; and (e) were focused, at least in part, on residential services. Search results, including full identifying information, were saved electronically. Documents were then selected from these search results to form a document database. Documents that were selected were acquired, entered into the database, and stored in hard copy form. To assure that the two team members were selecting documents using the same criteria, we calculated average agreement at 88.5% on selections made from three large search result files. In addition, we regularly discussed search results and selections at project team meetings. Once acquired, the reference lists of documents were also searched for additional items not previously identified. Approximately 250 documents were identified and acquired in this way to form a working database.

Documents in this database were read and a smaller number selected for specific review if they (a) were published in peer-reviewed journals; (b) included community-institution cost comparisons; (c) were referenced in the cost-comparison literature; and/or (d) included a unique methodological element or approach, were frequently cited in the literature, or were illustrative of a specific historical point. Because of these stringent criteria, only a

small sample of the documents are specifically reviewed herein.

Research Review

Peer-reviewed articles were selected for review in this section to provide a historical glimpse of the cost-comparison literature over the past quarter century. Studies were selected that have a bearing on policy issues in the field, especially those related to cost comparisons. A summary of some of the selected studies is provided in Table 1. Because absolute levels of costs are less important here than comparative costs, no attempt has been made to adjust costs to a common fiscal basis. Therefore, caution must be exercised because the studies span a broad time period. Although comparisons *within* studies are possible, costs may not be directly comparable, on a dollar basis, *between* studies because of inflation and other factors.

Murphy and Dattel (1976)

In this early cost-benefit analysis, Murphy and Dattel reported that a community-placement program in Virginia produced an average net savings, across 52 residents, of \$20,800 per resident over 10 years (range = \$13,000 to \$29,000) or, on average, \$2,080 per person per year. They noted that most of these savings accrued to the state rather than to the federal government. Murphy and Dattel used complex data collected across system elements, and their often-cited 1976 study is not without methodological problems. One concern is that participants were not representative of the MR/DD population in two ways. First, over half of the 52 individuals studied (61.5%) did not even have mental retardation or other developmental disabilities, coming instead from a rural facility for persons with mental illness, thus also possibly underrepresenting urban and suburban settings. Second, participants were screened, and those who were not likely to succeed in community placement were excluded. Admittedly, Murphy and Dattel's main purpose was to assign costs to benefits of community placement and was not a formal cost-comparison study per se. Despite this purpose, the study is often cited in the context of cost comparisons. Further, with regard to methodology, the authors noted that "90 percent of the data on costs and benefits over the ten-year period were based on *projections*" (p. 169, *emphasis added*). The basis of these projections was, on average, only 8.5 months of community living. Al-

Table 1 Characteristics of Reviewed Studies

| Source | Settings and subjects | Cost outcomes | Factors limiting generalization |
|------------------------------|---|--|--|
| Murphy & Datel, 1976 | N = 52; MH = 62% MR/DD = 38% (moderate, severe, or profound); Ss placed from 4 institutions in VA | Average net savings of \$2,080 per year per client in community services. Subgroup showing no cost-benefit from community placement, most similar to current institutional population | Mixed, nonrandom, nonrepresentative (of MR/DD) sample. No correction for severity or case-mix Sample screened to eliminate potential community placement failures 90% of data derived from estimates (based on 8.5 months of community placement) No accounting for start-up or capital costs Different cost-aggregation methods across groups; relied on self-report cost data from community providers, including estimates, compared to accounting records for institutions Rater differences across groups Exclusion of three high-cost community cases |
| Jones et al., 1984 | N = 140; 70 "movers" and 70 matched "stayers"; 85% severe or profound; drawn from Pennhurst facility in PA | Overall cost difference between community placement and public institution reported as \$6,886 per resident per year | No accounting for start-up or capital costs Small n-size in community setting No control for case-mix factors (i.e., community setting individuals not fully comparable to Fairview population) Few client characteristics provided to allow case-mix correction Day program costs were only estimates from budgets Community medical costs estimated from individual appointment records/documentation rather than billing encounter data |
| Schallock & Fredericks, 1990 | Fairview facility (OR) with census of 1,084 compared to 4 group homes and an apartment program (combined capacity = 25) | Average annual per person ICF/MR costs = \$59,412 compared to \$53,635 in community settings; costs in two group homes most similar to Fairview population = \$60,615; equalizing raw costs for staff levels, community settings were more expensive | No accounting for start-up or capital costs Small n-size in community setting No control for case-mix factors (i.e., community setting individuals not fully comparable to Fairview population) Few client characteristics provided to allow case-mix correction Day program costs were only estimates from budgets Community medical costs estimated from individual appointment records/documentation rather than billing encounter data |

(Table 1 continued)

Table 1 Continued

| Source | Settings and subjects | Cost outcomes | Factors limiting generalization |
|--|---|--|---|
| Nerney & Conley, 1992 | N = 375 living arrangements (group homes and nonfacility care) in 3 states (MI, NE, NH) compared with institutional costs | Institutional Care Rates (from records) Michigan: \$63,000 Nebraska: \$19,391 New Hampshire: \$28,411 Community Rates (corrected using 50% split on need) Michigan (non-ICF): \$47,359 Michigan (ICF): 48,487 Nebraska: \$25,778 New Hampshire: \$42,007 Overall cost savings in community of \$6,154 per person per year | Data collected at facility level; incomplete correction for case-mix factors Different cost aggregation methods across settings Extreme variability in costs Education and Medicaid-reimbursed costs excluded No accounting for start-up or capital costs |
| Knobbe et al., 1995 | N = 11; all severe/profound with challenging behaviors; placed from state facilities into homes serving 3 individuals | | No accounting for start-up and capital costs Estimates for community medical service costs appear to be underestimates |
| Campbell & Heal, 1995 | N = 1,295 "observations" of clients living in all settings in South Dakota | Average annualized adjusted rates reported as: ICF/MR = \$55,560 ICF/15 = \$39,077 HCBS = 25,813 Community Training Services = \$21,210 Costs found to be associated with client characteristics, agency characteristics, funding source, staff: client ratio, and certain geo-demographic variables | Possible case-mix problems given loss of 29% of community sample Artificially high cost prediction may be due to use of aggregate vs. individual cost data |
| Stancliffe & Lakin, 1998; Stancliffe & Hayden, 1998 | 116 individuals moved to community settings and 71 remaining in institutions in MN | Average per person annual costs: \$115,168 in institutions; \$84,475 in community settings | Medical and case management costs excluded from analyses Covariance methods may not have fully equalized groups |

(Table 1 continued)

Table 1 Continued

| Source | Settings and subjects | Cost outcomes | Factors limiting generalization |
|----------------------|--|---|---|
| Emerson et al., 2000 | 86 adults in village communities; 133 adults in new residential campuses; 281 adults living dispersed housing schemes (group homes and supported living) | Averaged annualized per person costs (converted from pounds sterling to 1997-1998 dollars): Residential campuses = \$74,516 Village communities = \$71,604 Dispersed housing in community = \$85,852 | Possible bias in at least one measure selected as a covariate Cost aggregation methods differed across settings No accounting for start-up or capital costs Overall system of services in UK may not be directly comparable with United States Non-random sample with relatively few exemplars of each model of service |

Note: Because the study by Rhoades and Altman (2001) is not strictly a comparison study and the authors use a national database, it is not included in the table. MH = mental handicap. MR/DD = mental retardation/developmental disabilities. S = subject. ICF = Intermediate Care Facility. HCBS = Home and Community Based Services.

though most subgroups showed some cost-benefit, the one group that did not show cost-benefit was the most similar to the current MR/DD institutional population.

Jones, Conroy, Feinstein, and Lemanowicz (1984)

This widely-cited cost-comparison study was conducted as part of the court-ordered Pennhurst Center (Pennsylvania) depopulation effort. In this study the authors reported an average cost difference of between \$6,500 and \$7,000 in favor of community residential facilities. Despite many citations in the literature, the study does not appear to have generated much critical scrutiny. At the time of the study, approximately 85% of the population of the institution was labeled as having either severe or profound mental retardation. Cost data were compared between a matched sample of 70 "movers" and 70 "stayers." Data on six types of service costs were collected: (a) residential, (b) day program, (c) entitlement (i.e., public assistance levels), (d) case-management costs, (e) medical costs, and (f) other costs. Because Jones et al. collected additional information on costs, their study extends an earlier matched comparison study of behavioral change (Conroy, Eithimiou, & Lemanowicz, 1982).

Despite the prominence of the Jones et al. (1984) study in the literature, there are several methodological problems that may compromise the generalization of findings. Five are cited by the authors: (a) the Pennhurst dispersal was under a court-order and was, therefore, unlikely to have a normative cost structure; (b) subjects were not randomly assigned to groups; (c) all community placements served only 3 or fewer individuals; (d) self-report data on costs from providers in community residential facilities were used; and (e) medical costs were not fully enumerated. In addition, the data-collection design allowed for different methods of data collection across groups. At Time 2 (postrelocation) in this study and its precursor (Conroy et al., 1982), data for 40 of 70 movers (57% of those who moved to community facilities) were collected by "county workers," whereas this was not the case for stayers (i.e., those who remained in the institution). Data for stayers were collected by a team of trained workers who used teams of professionals as respondents. Furthermore, those who collected the behavioral data at Time 1 were not the same as those who collected the data at Time 2 for any subjects. Thus, raters were different between Time 1

and Time 2 and, for 40 out of 70 movers, were different from those rating all of the stayers at Time 2. In addition, as the authors stated, the interrater reliability of the behavioral data-collection instrument, the Behavior Development Survey, "has been shown to be barely adequate" (Jones et al, 1984, p. 306). Similar problems in methodology appeared in the collection of cost data.

For example, the authors did not explicitly examine the extent to which the different cost-estimation methods in the community and the institution may have yielded systematic biases in the data. In the community, costs were obtained by phone contact, with some costs being based on estimates made by one administrator in a county; these estimates were then applied to all individuals in that county. In the institution, by comparison, the operating costs were derived from state billing rates and examination of financial records. These differences in cost-aggregation methods, especially the reliance on broadly applied estimates in community settings, raises the possibility of systematic error. It is noteworthy, given the problems delineated here, that the authors themselves noted difficulties in making valid cost comparisons between community settings and institutions, including the difficulty in capturing costs, the heterogeneity of settings, and the fact that costs can be shifted between the state and federal governments.

More problematic in the present context is that the authors identified "three people living in community facilities with extremely high costs (\$77,578, \$103,679, and \$104,565)" (p. 308) and excluded them, arguing that they were statistical outliers. It is not uncommon for investigators conducting fiscal analyses in human services to find that a small segment of a population accounts for a proportionally large share of costs. Extreme values such as these likely represent *real* costs, despite the fact that in a *statistical* sampling distribution they appear as outliers. Excluding such data may have seriously skewed the cost findings. A better strategy would have been to analyze the data with the so-called "outliers" left in the dataset and then reanalyze the data with the outliers removed, thus allowing comparison of the overall effect of such cases.

Schalock and Fredericks (1990)

In a study comparing the Fairview facility in Oregon with four group homes and an apartment program, Schalock and Fredericks (1990) reported

an average cost of \$59,412 in the ICF/MR institutional facility compared to an average cost of \$53,635 in community residences. They attributed the average cost difference primarily to staff salary levels and noted that if corrections were made to equalize salary levels, the institutional facility would actually have been less expensive. Certain methodological problems were noted in this comparison as well.

For example, of the 1,048 individuals in Fairview at the time of this study, most had profound disabilities and fewer than 100 (< 10%) were school age, yet all of the community settings but one provided services to children. Furthermore, two of the comparison group homes provided services to children with mild mental retardation and emotional problems or disturbances. When considering only the two group homes serving residents who were most similar to the Fairview population, the community settings are found to be more expensive than the institution (*without* correcting staff salaries). One of these group homes served individuals with severe motor and ambulation problems who were incontinent and who, with the exception of one individual, needed to be fed by a staff member. The other home served children with profound mental retardation, some ambulation problems, and challenging behaviors. The average costs in these two facilities was \$60,615, or slightly more than the Fairview average cost. These authors concluded that:

These data present some troubling facts, especially for staunch advocates of deinstitutionalization. A general conclusion can be drawn from these data that, for individuals with challenging behaviors, residential costs within the community cost approximately the same as institutional services in Oregon, given the current salary rates of institutional and community residential staff. When these data are extrapolated, to equalize staff salaries between the institution and the community residence, the conclusion must be drawn that large institutions are, in most instances, less expensive than community residences for these challenging populations. (p. 283, emphasis in original)

Nerney and Conley (1992)

In this large-scale analysis of costs in regions of 3 states (Michigan, Nebraska, and New Hampshire), Nerney and Conley (1992) compared institutional costs and costs in community-based settings (including ICF and non-ICF group homes in Michigan). An array of cost data were collected from community settings, including direct-care and family-care payments (costs of care givers' operations/administrative costs, transportation costs,

medical/clinical costs (other than those paid by Medicaid or other third-party payers), day program costs, and other costs. Data were not collected on educational costs or Medicaid-reimbursed health care costs. Data on institutional services in these regions were collected from overall state cost reports. The institutional data were not collected in the same way as the community cost data (i.e., state developmental disabilities offices provided the rates), a methodological problem shared by much of the research in this area.

The overall costs of services to community-based individuals in the specified regions of Michigan, Nebraska, and New Hampshire were \$38,098, \$19,391, and \$28,411, respectively, compared to state rates for institutional care, which were \$63,000, \$32,000, and \$72,000, respectively. The community rates in this study, however, include *both* facility (i.e., group home) and non-facility (i.e., apartment, family, and foster care arrangements). Taken separately, and partially corrected for case mix by examining the 50% of settings with "high need" individuals, the differences between group home rates and institutions in Michigan were reduced to \$15,641 (non-ICF) and \$14,513 (ICF); in Nebraska they were \$6,222; and in New Hampshire, \$28,993. Factoring in the Medicaid medical costs and applicable education costs would further attenuate the reported community-institution cost differences.

The interpretation of these findings remains difficult for several reasons. First, data were collected at the level of *facilities* rather than *individuals*. It is likely that there are substantial differences, in each of these 3 states, between the population that resides in their community group homes and the population residing in their institutional settings. It is unlikely that the level of need analysis (a 50% split) fully accounted for such variability (i.e., fully corrected for case-mix factors). Second, as noted, the procedures for aggregating costs differed between the community settings and the institution, and certain costs, as the authors noted, were excluded (e.g., health care costs covered by Medicaid or start-up and capital costs). Third, although the Nerney and Conley (1992) provided separate estimates, the aggregation of all community settings (i.e., facility and nonfacility community settings) de-emphasizes the cost differences *within* community settings. That is, they reported "enormous" variability both within and between states. For example, in Michigan, costs in 11 community place-

ments were under \$10,000, whereas costs in 4 others were over \$60,000.

In accounting for the differences between community and institutional placements, Nerney and Conley (1992) noted that staffing was a primary variable, given that between 50% and 75% of all of the program costs are associated with staffing. For example, they noted that a substantial portion of the differences in costs between Michigan and Nebraska could be directly attributed to a staffing ratio in Michigan that was 1.62 times higher than in Nebraska.

Knobbe, Carey, Rhodes, and Horner (1995)

Although employing a very small sample ($N = 11$), Knobbe et al. reported a more complete cost-aggregation methodology than is typical in this area. Similar to Schalock and Fredericks' (1990) work, all of the participants had either severe or profound mental retardation and exhibited challenging behaviors and/or mental health problems, thereby providing an interpretive link to current institutional populations. A strength of the Knobbe et al. study is that it is longitudinal; the authors followed the participants who moved from large centralized state facilities to community settings of three individuals each (thereby avoiding case-mix problems). These authors aggregated costs in 16 distinct categories, between 1988 and 1990, including food, medical, utilities, administrative costs, staff training, transportation, insurance, gas/vehicle maintenance, and others. Unlike Jones et al. (1984) and Nerney and Conley (1992), community costs were collected by Knobbe et al. in a way that was similar to how institutional costs were collected. They reported an average yearly cost per resident for the 11 individuals in the community during 1990 as \$111,123 compared to their last year in the institution, which cost \$117,277 (adjusted for inflation). The difference in costs across the settings was \$6,154.

With regard to cost shifting, there was a rather large discrepancy between medical costs in the two settings, with institutional medical costs being more than five times greater than costs in the community (\$10,939 vs. \$2,144, respectively). The estimate for medical costs in the community settings is low considering health care cost findings in this population. For example, interpolating an annual cost for health care services, for 1990, from available literature (e.g., Adams, Ellwood, & Pine, 1989; Kronick, 1997; Kronick, Dreyfus, Lee, & Zhou, 1996)

suggested that a reasonable annualized estimate for all health care costs (i.e., inpatient and outpatient costs) for this population would have been between \$4,000 and \$4,500, which would account for much (about 38%) of the community versus institution cost difference found in this study.

Although Knobbe et al. (1995) employed a commendable methodology for aggregating costs, we note that neither start-up costs nor capital costs were included in the cost estimates. Nevertheless, these kinds of expenditures are real costs associated with developing community settings and, arguably, should be amortized and entered into the cost-comparison research. Mitchell et al. (1990) noted this issue in their review and commented that it is possible that such costs during rapid deinstitutionalization periods actually cause costs to rise sharply and then return to lower levels. In most of the studies reviewed herein, none of the authors accounted for either community or institutional capital costs or community start-up costs nor was there any correction for costs necessary to pay for state-operated regional and community offices that would not be necessary in an institution-only system.

Campbell and Heal (1995)

Campbell and Heal (1995) employed complex statistical modeling techniques to predict costs of services attributable to facility location, size, funding source, and level of client functioning. They reviewed the literature and indicated that the results of many cost-comparison studies can be challenged because of (a) the difficulty in aggregating costs equitably across community and institutional settings and (b) the lack of comparability in the institutional and community-based groups with respect to functioning level and care needs (i.e., case mix). In their 1995 study, these authors endeavored to address these problems.

Campbell and Heal (1995) examined 1,295 observations in South Dakota of individuals of all ages in 79 service groups, which were combinations of different provider agencies, funding sources, and residential service types. Data were collected on average daily costs that were comprised of seven cost centers (administration, support, room and board, etc.); in addition, the analysis included the average daily reimbursement rate for these services as well as staff-to-client ratios. The statistical analysis linked these data to characteristics of service location, agency characteristics, client characteristics, and service funding class as well as to a set of other

demographic variables (e.g., city population, county unemployment rate). A substantial portion of individuals in community settings (29%) were excluded from consideration for various reasons, whereas all but 2 individuals in the two institutions represented were included.

In the analysis, mean average daily costs for the different funding classes, adjusted for community, agency, and client characteristic variables, were (annualized): \$55,560 (ICF/MR); \$39,077 (ICF/15, i.e., a 15-bed ICF/MR facility); \$25,813 (HCBS); and \$21,210 (Community Training Services). In a related analysis staff ratios were found to be significantly higher for the ICF/MR settings, which accounted, in part, for the cost differences. Still, the difference across ICF settings (i.e., ICF/MR vs. ICF/15) is striking and suggests that different factors may be included in the cost bases. In addition, certain geodemographic variables (city unemployment rate, population size), along with client functional and behavior characteristics, predicted over 73% of the variance in costs. Adding provider characteristics (e.g., facility size) and funding source (ICF/MR, ICF/15, or HCBS) increased prediction to over 90%. Thus, a great deal of the variability in costs was associated with (a) provider and client characteristics (clients with more intense needs required more expensive services), (b) funding sources, and, interestingly, (c) characteristics of the locale. This last finding echoes the large cost differences across states that was reported by Nerney and his colleagues in the 3 states they studied (Michigan, Nebraska, and New Hampshire).

Exclusive of the institutional placements, Campbell and Heal (1995) found that community services costs bore a U-shaped relation to agency size, with large and small agencies being *more* costly than intermediate-sized agencies. This study, although analytically complex, provides no direct comparisons of costs across comparable groups; rather, the authors sought to predict costs (and other variables) based on a wide assortment of data. Large-scale studies such as this one are important and complement controlled group comparison studies.

One finding of special interest in the Campbell and Heal (1995) study was the strong predictive nature of client characteristics on costs. This finding is in juxtaposition with certain earlier findings. For example, Ashbaugh and Nerney (1990) concluded that client characteristics were *not* related to expenditures. Stancliffe and Lakin (1998) reported

a similar lack of relation between expenditures and client characteristics. The finding of a relation by Campbell and Heal, however, is important, because predicting 65% of the variance in costs shows that client characteristics *do* matter in service costs.

Stancliffe and Lakin (1998) and Stancliffe and Hayden (1998)

In these two studies, both conducted at the University of Minnesota, the authors drew their participants from 190 individuals enrolled in an ongoing longitudinal study. Expenditures and outcomes for 116 individuals with severe and profound cognitive impairments following movement to community settings and 71 individuals who remained in institutional facilities were studied. Stancliffe and Hayden (1998) followed the 71 individuals who did not move to community placements. Because cost analysis is rather secondary in the Stancliffe and Hayden study, our focus here will be the study by Stancliffe and Lakin (1998) in which "movers" and "stayers" were compared.

Although Stancliffe and Lakin (1998) made comparisons based on residential costs as well as total costs (residential costs + day program costs), comparisons between community and institutional settings were only conducted on total costs due to the aggregation methodology. These comparisons were reported for both raw and adjusted data using resident:staff ratio as a covariate, based on staff members available on weekday evenings. Stancliffe and Lakin reported significant differences in both raw and adjusted average daily total expenditures between community and institutions. Costs for residents in community settings (annualized: \$84,475) were 36% less than costs for residents in institutional settings (annualized: \$115,168).

Some of the problems identified in this research area, such as case-mix issues, appear to be resolved by the use of statistical analyses using covariates. However, taken together, statistics from both of these articles (Stancliffe & Hayden, 1998; Stancliffe & Lakin, 1998) suggest that certain selection factors may still have been operating that affected the outcomes and conclusions. For example, it appears from the data that a behaviorally challenging group may have been initially overlooked for community placement, requiring the state to develop public community ICF/MR settings. In addition, Stancliffe and Hayden presented statistics on therapy use in the stayers group, suggesting that many of them had severe physical dis-

abilities. It is possible that some of these differences were not apparent in significance testing due to the reactivity of certain measures (e.g., using the ICAP Broad Independence score as a measure of adaptive behavior).

In addition, one of the variables used as a covariate, resident:staff ratio on weekday evenings, may have unduly penalized the institution relative to the community sample. Differences in staffing ratios across the day may simply be a proxy for differences in setting characteristics. For example, it is likely that the assessment of overall resident:staff ratios would have attenuated setting differences because in ICF/MR settings, there are many therapists available during the day that cannot be counted on weekday evenings. In an ICF/MR setting with residents who have multiple disabilities and restricted functioning, many resident training programs are likely to be active during the day, when specialized staff members are available to carry them out.

It is also the case that staffing levels in public ICF/MR settings that are slated for downsizing or closure may not be representative of typical staffing ratios. It is likely that, due to civil service rules, unionization, and so forth, that a lag exists between the reduction in census and the reduction in staff. In the studies conducted by Stancliffe and his colleagues, data were collected during a 4-year transition period as staffing levels were adjusted down in the institution and up in the community to accommodate the shift in consumers. Because staffing reduction in institutional settings almost certainly proceeds slower than staffing up in community settings, staffing ratios in these studies may be somewhat suspect and, as a covariate, are likely to have affected many of the analyses.

Finally, the exclusion of medical, case management, and capital costs no doubt affected the comparisons. We have already addressed the issue of the medical costs shifting from ICF/MR costs to other sources (e.g., private insurance, Medicaid fee-for-service). However, given the complexities of the community-based population described in these studies, it is not unreasonable to conclude that additional case management costs would accrue in the non-ICF/MR settings compared to the institution and community ICF/MR settings.

International Cost-Comparison Research

Although the main focus of the present review is the United States, there is a substantial body of literature from other countries that cannot be ig-

nored. This literature is, in some ways, strikingly different than the American literature. Felce (1994) reviewed the research on cost studies in the United Kingdom and explored what he characterized as a consistent finding that community services were more expensive than institutional services, in juxtaposition to the perception of many in America. For example, Emerson and his colleagues, who also studied costs in the United Kingdom, cited a previous meta-analysis that "adjusted costs . . . reported for hospitals [institutions] ranged across studies from \$799 to \$1,540 per week, whereas costs reported for group homes ranged from \$912 to \$2,750 per week" (Kavanagh & Opit, 1998, quoted in Emerson et al., 2000, p. 83, material in brackets added). Underlying the differences in cost-comparison research in the United Kingdom and America may be differences that exist in the service systems. For example, in America states share costs with the federal government in complex ways that promote cost shifting as state systems expand community systems relative to institutions. Because the costs that can be shifted under Medicaid programs differ and are not clearly understood by many, a perception may have arisen that there is no diseconomy of scale in smaller facilities. In contrast, because funding formula are less complex in the United Kingdom, it is assumed that community care will be more costly; in some ways just the opposite of the American view.

Still, Felce (1994) concluded that smaller community-based facilities offer the potential for increases in certain aspects of quality of life and that, in the long run, may be economically affordable. However, he cautioned that very small placements (i.e., smaller than 4) may not be able to maintain favorable costs structures if additional staff members are required based on increased needs of residents.

Recent work in the United Kingdom by Emerson and his colleagues (Emerson et al., 2000) found that costs associated with dispersed housing (i.e., housing that is integrated into existing communities) were 15% higher than those of residential campuses (i.e., institutions) and were 20% higher than village communities (i.e., clustered housing similar, in some ways, to regional centers and certain private facilities in America). After the authors adjusted for both adaptive behavior and challenging behavior, the annualized per person cost in 1997-1998 dollars (converted at £1 = \$1.63) for village communities was \$71,604; for residential campuses,

\$74,516; and for dispersed housing in the community, \$85,852.

In a multivariate study conducted by Felce and his colleagues in Wales (Felce et al., 2000), total accommodation costs were predicted from resident and setting characteristics, setting size, service processes, and indicators of quality. These researchers derived a two-factor regression solution predicting accommodation costs that included service model and client characteristics (Adaptive Behavior Scale [ABS] scores) that accounted for 51% of the variance in costs, adjusted $R^2 = .48$. Unlike the findings in America, costs in this model were found to be *lower* for institutions in comparison to community settings. Similar to some of the research conducted in the United States, client characteristics were important in predicting costs. According to Felce et al., the cost differences between service models were related to client characteristics, such that “costs tended to be higher for people with lower ABS scores within each service model. . . (and that) the consistent finding of UK research on deinstitutionalization is that community services are more expensive than institutional services” (p. 321).

At present, there is speculation as to what forces produce this juxtaposition of cost differences between the United Kingdom and the United States. Stancliffe, Emerson, and Lakin (2000) suggest that “one factor contributing to higher institutional costs in US studies may be that many US institutions have been downsized to the extent that relatively fixed institutional infrastructure and running costs are distributed over a small and diminishing population” (p. iii). This is precisely the interpretation offered by Braddock et al. (1991). This view is further echoed by Felce and his colleagues and has been voiced elsewhere in the literature. In addition, the work by Felce and his colleagues (2000) also assessed quality of life and noted that “This analysis provides additional evidence of a weak linear relationship between resource inputs and service quality, even after controlling for service recipient characteristics” (p. 323).

Rhoades and Altman (2001)

Using data from the 1987 National Medical Expenditure Survey (NMES), Rhoades and Altman (2001) used a different approach to studying costs in MR/DD services. In this survey, instead of taking the typical perspective of average aggregated costs from samples of individuals across settings, they de-

rived data at the *individual* level. That is, individuals were sampled, and then asked about their individual costs. Rhoades and Altman began by noting that despite the success of deinstitutionalization, problems remained, including (a) the more intense needs and, thus, associated increased costs, of those who remain in congregate care facilities and (b) the declining cost-benefit of community settings compared to institutional settings. These problems prompted the recognition that now that the field has effectively deinstitutionalized many individuals, “the remaining population, more likely to have multiple problems, is generally a population that would generate higher expenditures no matter where they are located” (p. 115).

From this perspective Rhoades and Altman (2001) conducted a multiple regression analysis that, among other things, predicted mean daily expenditures by several categories of person variables and facility characteristics. The authors extended the work done by researchers such as Campbell and Heal. Rhoades and Altman reported that:

The results of the multivariate analysis indicate, at a national level, what Campbell and Heal (1995) found in South Dakota. Facility characteristics, resident characteristics, and even community resources play a part influencing daily expenses for residents in facilities both large and small. . . . The results also show that for persons with borderline, mild, moderate, or severe levels of mental retardation, it is more expensive to provide care in larger facilities. For individuals with profound mental retardation, the size of the facility is not a factor in daily expenses once the increased expenses for the level of mental retardation are considered. (pp. 123–124)

In a way, the Rhoades and Altman study (2001) was the beginning of the shift in the literature away from controlled comparison studies. Instead of using static comparisons to determine specific costs in a policy-making context, results of this study suggest that researchers should approach the problem from the perspective of the individual and identify the most favorable placement based on the characteristics of the person and the service setting together. The authors showed, for example, that resident characteristics were, indeed, associated with costs of care regardless of the setting. Perhaps even more interesting is the interaction with level of mental retardation such that “Persons with similar levels of dependence had different daily expenses, related to their level of mental retardation and, thereby, the ability to cooperate and communicate with caregivers” (p. 126). This work is important because the results suggest questions that relate specific needs of individuals to specific re-

quired services independent of the setting. Again, in the words of Rhoades and Altman:

It is important to understand how organizational type, resident characteristics, number and types of services, and location come together to influence expenditures in order to develop the necessary resources for proposed health care delivery plans. Examining expenses from the individual rather than the organizational perspective allowed us to examine this complicated puzzle in a different way. (p. 127)

In such a context the question: "What costs more, community or institutions?" or "Which type of setting serves an individual better?" is no longer the critical question. Adopting the approach implied by Rhoades and Altman (2001), it becomes clear that costs and expenditures are related to the needs of the person, the quality of services provided, the desired outcomes, and perceived satisfaction on the part of the individual.

A Word on Outcomes

Although we are aware that the issues of quality of services and service outcomes necessarily go hand in hand with costs, the empirical association between costs and quality is less established when a broad array of research findings are examined. For example, positive outcomes reported in the literature associated with deinstitutionalization and community-based services include increased choice (Stancliffe, 2001; Stancliffe & Abery, 1997), behavioral improvement (Kim, Larson, & Lakin, 2001), improved social interaction of certain segments of the population (Anderson, Lakin, Hill, & Chen, 1992), integration in rural settings (Campbell, Fortune, & Heinlein, 1998), and inclusion in various day-to-day activities (Campo, Sharpton, Thompson, & Sexton, 1997; Emerson et al., 2000). However, such positive findings need to be considered in relation to findings of increased mortality in community settings (Strauss & Kastner, 1996; Strauss, Kastner, & Shavelle, 1998; Strauss, Shavelle, Baumeister, & Anderson, 1998; see also Taylor, 1998), problems in vocational services and employment (Stancliffe & Lakin, 1999), and problems of Individual Habilitation Plan objectives and behavioral technology (Stancliffe, Hayden, & Lakin, 1999, 2000). Recent work has also highlighted problems in access, utilization, and quality in community-based health care and personal care for people with mental retardation and developmental disabilities (Knobbe et al., 1995; Larsson & Larsson, 2001; Walsh & Kastner, 1999). Emerson and his

colleagues (2000) identified higher rates of verbal abuse and relatively greater exposure to crime among individuals who lived in dispersed community settings. Finally, Felce and Perry (1997) reported that in the community settings they studied, staff members generally lacked organized approaches and skill sets to promote development in those living in the settings in which they worked.

Although the assessment of consumer satisfaction and quality of life has been reported often in HCBS settings, in other evaluation reports, investigators (e.g., Lutsky et al., 2000) have noted a set of specific concerns around quality of care, as did LeBlanc et al. (2000). As stated by Lutsky and his colleagues, these concerns include (a) difficulty in state monitoring of noninstitutional care because of their dispersed nature, an increasing problem as more HCBS placements have been created; (b) inexperience in monitoring noninstitutional care, in some states including a lack of regulations and licensing requirements; and (c) the potential impact of low provider reimbursement rates on the quality of care. In the words of Lutsky et al. (2000): "The effectiveness of licensing and regulatory requirements at ensuring quality of care is impaired if states do not sufficiently monitor compliance. However, monitoring quality of HCBS services may present greater challenges than monitoring quality in institutional settings" (p. 28).

It may also be the case that quality of care and quality of life differ across community and institutional settings in their importance to stakeholders. For example, as institutions increasingly provide services to people with severe and profound cognitive deficits, complex needs, challenging behaviors, and diminishing skills, concerns about quality of care may outweigh those of satisfaction. In community settings, on the other hand, with a more heterogeneous and able population, it may be that quality of life, satisfaction, and interest in self-determination takes on more importance. Thus, the assessment of both quality of care and quality of life, although related and important in both settings, may need to be adjusted for characteristics of the setting in which they are assessed.

Therefore, we agree with Emerson (1999) that outcome measurement be expanded beyond assessment of personal outcome measures, such as choice and community involvement, to include a greater emphasis on health and safety. As Walsh and Kastner (1999) have pointed out, health and safety outcomes have been underrepresented in the MR/DD

literature (cf. Hughes, Hwang, Kim, Eisenman, & Killian, 1995). Outcome measurement needs to include direct indicator and benchmark assessment of outcomes based on clear standards. For example, individuals with profound disabilities and multiple disabling conditions may benefit from measures evaluating (a) access to comprehensive health care services (primary, psychiatric, and dental care as well as ancillary services, including care coordination); (b) rates and status of abuse/neglect reports and investigations (including victimization in the community); (c) mortality review; (d) access and utilization of behavioral services; and (e) similar direct measures.

Discussion

In this review of selected peer-reviewed studies, we have documented the complexity of research examining costs of community and institutional service models and show how methodological problems affect conclusions. The work reviewed here spanned a quarter-century during which time the field was in constant transition. Early studies were designed simply to show the cost-benefit of community placements (e.g., Murphy & Darel, 1976), whereas more recent work has highlighted the complex multivariate nature of the area and recognized the need to identify costs at the individual level (Rhoades & Altman, 2001). The shifting cost structures across settings during the period reviewed, and the heterogeneity of the population served, prompts the conclusion that the question "Which is less expensive, institution or community?" is the wrong one to ask. Rather, the questions that need to be asked revolve around the individual (i.e., "What does this person need? Where is the best place to provide for these needs?" and "at what cost?").

The research reviewed here suggests, in several ways, that community placements are not inherently less expensive than institutions. First, there is an intrinsic lack of comparability between institutions and community settings. For example, community services include a diverse array of service types, ranging from minimal intermittent supports to residential and day program services, whereas institutions traditionally offer an established service package (e.g., ICF/MR services). Thus, only a part of the range of community services is comparable with the services received in a large ICF/MR. Researchers comparing costs need to assure that the service packages are comparable across settings, a

challenge given the inherent differences in these service systems. Second, during deinstitutionalization efforts, the ability to shift certain community costs to programs other than those administered by a particular MR/DD state agency will lead to reduced costs *within* that specific governmental division or authority. However, the overall cost to society may not be reduced. For example, medical costs within an ICF/MR are clearly part of the budget of the state MR/DD authority; however, when an individual moves to a community setting, medical expenses can often be shifted to another funding source (e.g., the component of state government that administers Medicaid health care benefits). Third, the apparent cost savings in community settings, to the extent that it is found, is often directly related to staffing costs. Results of the research reviewed herein suggest that the modest differences reported for community services are predominantly the result of lower staffing costs in privately operated community settings compared to state-operated settings. However, the lack of parity between staffing costs in institutions and community settings is not a desired efficiency. In fact, it is likely that any initial cost benefits claimed for community settings will be difficult to sustain as individuals with more complex needs are served in these settings. Further, over time, it is possible that the disparity between community and institutional cost structures for staffing will diminish as community workers and advocates strive to achieve parity in compensation with respect to state workers. Results of the present study suggest that the area of staff compensation deserves further study.

These elements of complexity in community-institution cost comparisons give rise to several recurring methodological problems. These problems include (a) the lack of comparability between groups based on biased, nonrandom, or convenience samples; (b) the lack of adequate case-mix controls; (c) differences in data-collection and cost-aggregation methods across groups; (d) the exclusion of critical categories of costs, such as medical expenses, case management, start-up, and capital costs; and (e) extreme variability in costs, cost shifting, and statistical-modeling problems.

These methodological problems limit generalization across settings. Three especially challenging methodological problems deserve special mention. First, few of the studies reviewed herein completely accounted for case-mix factors. Given the heterogeneity of the population of individuals with MR/

DD and the near impossibility for random assignment to residential settings, complex case-mix factors are always present. Longitudinal studies and multivariate studies using statistical controls (e.g., employing covariate methods) offer promise as long as care is exercised in the selection of variables. Ideally, covariates that include both cognitive and adaptive measures should be included, although this was not typical of the studies we reviewed.

Second, cost-aggregation methods varied widely over the reviewed studies. Often, the cost-aggregation method used in community settings was different than the way costs were identified in facility settings. In our review, researchers who employed more complex and complete cost-aggregation methods typically found smaller, if any, community-institution differences. In studies from the United Kingdom, which seem to be less susceptible to methodological artifacts (such as cost shifting or inability to estimate costs), researchers typically reported increased costs in community settings.

Third, elements of costs were routinely excluded in even the best studies reviewed here, sometimes because they were shifted to other funding sources and sometimes because the data were unavailable. In both cases it is not acceptable to assume that the effects of costs that are shifted or excluded are the same in the comparison groups. We have noted, for example, that many service costs are *built into* the ICF/MR model. The costs incurred for supporting community infrastructure for such costs cannot simply be excluded from the cost-comparison analyses. Related to this, an inherently difficult fiscal problem is the inclusion of start-up and capital costs incurred in community settings compared to long-term state ownership of institutional facilities. Excluding these categories of costs is not justifiable, and researchers need to identify methodologies that include these costs (e.g., Emerson et al., 2000). In conclusion, in nearly all of the studies reviewed, certain specific costs were excluded from the analyses, thus limiting the generalization of results.

From the cost studies reviewed here, it is clear that large savings are not possible within the MR/DD field. That is, the costs of residential care, regardless of setting, involve a specific amount of resources that vary, somewhat predictably, with staffing levels, client characteristics, and other variables as in the studies reviewed. These studies do not support the view that large cost savings are possible. In fact, researchers who conducted the studies re-

viewed here that employed more sophisticated and complete cost-aggregation methods tended to find the smallest differences across settings (e.g., Knobbe et al., 1995; Schalock & Fredericks, 1990).

Although this review provides a unique historical overview of research in this area, it is not without limitations. First, we restricted our selection of studies to those that were peer-reviewed and addressed the issues under consideration. We narrowed our selection to peer-reviewed studies for quality control reasons and because, for example, unpublished state-level reports might be especially susceptible to cost-shifting effects. A cursory review of many of these reports, however, suggested that their inclusion would not substantially alter our conclusions. Second, we did not directly review the outcomes literature, although, as we have noted, we believe it to be critically important in this field. Third, the scope of this work did not allow us to review cost comparisons made between different community settings, although published work is beginning to appear in this area and will prove to be more critical in the future. We believe that the methodological considerations presented herein will continue to be important as that literature grows.

In the final analysis, it appears that the costs of caring for people with MR/DD will be highly variable across settings and will vary with the characteristics of those served and the resources, especially staffing, devoted to serving them. Because this population ranges from individuals who are barely distinguishable in the general population to individuals who require high levels of sophisticated care, it is likely that a range of service models will continue to be needed. In the future, researchers who conduct studies that will best inform public policy are likely to be those employing multivariate methods to take such heterogeneity into account. As we have documented here, movement toward such research models is already underway.

Based on the analysis presented here, the choices made by governmental agencies about the relative mix of service types should include a consideration of consumer needs rather than being made solely on the basis of local service costs. It is also important to take into account the values of those who use the services.

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